



Doctorate in Educational Psychology

“It’s the fact they’re no trouble to anybody. That’s the problem, isn’t it?”: An exploration of the characteristics of Selective Mutism and their applicability for the role of the Educational Psychologist.

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Summary

This thesis is divided into three sections:

Part 1 is a detailed literature review which explores relevant research into the characteristics of Selective Mutism (SM), the co-morbid conditions of the diagnosis and how the condition is within the remit of Educational Psychologists (EPs). The review begins with a description of Selective Mutism (SM) including its history, prevalence, and aetiology. It then describes the characteristics noted in the literature. This is followed by the impact of SM, co-morbidity and misdiagnosis. Followed by the role of the EP in relation to the condition. Finally, the rationale for the current study is explained, with mention to the research questions.

Part 2 is the empirical study, which explores the characteristics of SM and if awareness of these characteristics would be beneficial in helping EPs elicit testable hypotheses. A summary of the relevant literature is discussed, followed by details of the methodology and procedure for the study. Forty-six parental questionnaires were completed, which were analysed using descriptive statistics and three EPs took part in a virtual focus group, which was analysed using thematic analysis (TA). Tables showing the differences in mode scores for the parental questionnaires and main themes and sub-themes of the focus group are presented in the results section. With both findings merging within the discussion, in order to discuss findings in relation to the research questions, along with relevant literature and psychological theory. Finally, future research and limitations are discussed.

Part 3 is the critical appraisal, which is a reflexive account of the studies contribution to knowledge and is a critical account of the research practitioner. This section discusses the development of: The research topic; rationale and research questions; the research paradigm; and the research design, whilst also discussing some obstacles that were encountered, the overall contribution to knowledge and practice and dissemination of the results.

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List of abbreviations

SM- Selective Mutism
SAD- Social Anxiety Disorder
ASD- Autism Spectrum Disorder
USA- United States of America
EAL- English as an Additional Language
MEAR- middle-ear acoustic reflex
MOCB- medial olivocochlear bundle
BICS- Basic Interpersonal Skills
CALP- Cognitive Academic Language Proficiency
ODD- Oppositional Defiant Disorder
GAD- Generalised Anxiety Disorder
OCD- Obsessive Compulsive Disorder
CNTNAP2- Contactin-associated protein-like 2
Dup7- 7q11.23 duplication syndrome
SMQ-R- Selective Mutism Questionnaire-Revised
AQ- Autism Spectrum Quotient
TD- typically developing children
SMIRA- The Selective Mutism Information and Research Association
EP- Educational Psychologist
SEN- Special Educational Needs
HCPC- Health and Care Professions Council
TA- thematic analysis
CAMHS- Child and Adolescent Mental Health Service

**some terms used within the literature review are outdated or could be seen as offensive (faulty family systems, neurotic relationships, impaired and mental retardation). However as these are the terms that have been commonly used in the area, this is what the author is trying to reflect, it does not mean that the author agrees with this terminology.

***Full stops used within the transcription process are to indicate when participants paused for a considerable time.



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Part 1: Literature review

Word count: 13,014

Chapter Summary

The literature review begins with a description of Selective Mutism (SM) including its history, prevalence, and aetiology. It considers the literature relevant to the characteristics of SM. As characteristics of SM is an area which has very limited research, co-morbid conditions of the diagnosis are also explored such as psychiatric conditions, chromosomal conditions and ASD as it has been documented that individuals with SM often have co-morbid conditions (Alpaslan et al. 2016). Therefore, key theories and studies are cited and critically evaluated which link directly to the research questions.

Purpose

The literature review aimed to answer the following questions:

- What are the characteristics of SM?
- What is the rate of co-morbidity? and
- What are the complications associated with misdiagnosis and how prevalent is this?

and takes a narrative review stance, following the guidance of Siddaway et al. (2019). A narrative review was chosen specifically because the researcher wanted to review literature with diverse methodologies; and wanted to connect studies that are on differing topics such as SM, SM and co-morbid conditions and the role of the EP and SM to explore a potentially new area of SM research as specific characteristics of SM have not been highly researched. The areas discussed are justified because they are based upon the main topic of the thesis (SM) and they relate to the research questions exploring the characteristics of SM and their applicability for the role of the EP. In particular, literature regarding co-morbid conditions and subsequently misdiagnosis is included as it is argued that it is pertinent to the first research question, as in order to know specific characteristics of SM professionals must first be aware of possible co-morbid conditions and of possible biases which may occur during diagnosis. It is beyond the scope of the review to cite medical interpretations of SM as it is not within the remit of characteristics; the researcher argues that it is in fact too far removed from the research questions and this review is interested solely in the characteristic level.

Key sources

The sources used to conduct the literature review were PsycINFO, web of science and SCOPUS. Search terms were:

- 'Selective mutism' 'selective mutism OR Selective Mut*' 'selective mutism OR Selective Mut* AND characteristics', 'selective Mutism OR Selective Mut* AND comorbid' and 'Selective Mutism OR Selective Mut* AND comorbid* AND Autism OR Autism spectrum disorders OR Autism spectrum conditions', 'Selective Mutism OR Selective Mut* AND comorbid* AND Autism OR Autism spectrum disorders OR Autism spectrum conditions OR Asperger*' for Psycinfo
- 'Characteristics AND of AND Selective AND Mutism', 'Selective AND Mutism AND Comorbid', 'Selective AND Mutism AND Misdiagnosis', 'Selective AND Mutism' 'selective mutism' and with keyword Selective Mutism and 'Selective Mutism AND misdiagnos*' on for SCOPUS, it was found that Mut* caused difficulties for this particular search engine.
- 'Selective Mutism AND Characteristics' for web of science, as the researcher had completed two full searches with a substantial number of overlaps, it was felt that a specific search within web of science was justified in order to ensure papers were relevant as opposed to having a large volume of unwanted papers.

As it was a narrative study there were minimal explicit inclusion and exclusion decisions, please see part three for more explicit exclusion criteria, therefore literature was drawn from not only the United Kingdom, but other areas also, based on relevance. However, the majority of papers were Western based, where there appears to be a shared understanding of SM. Literature is also cited from workshops from Maggie Johnson's selective mutism webinar in 2020, EP CPD in 2020, the SM H.E.L.P. Summit 2021 and gathered from the bibliography of papers found through the search engines. Previous authors were also contacted in order to access and ask questions relating to unpublished research; however, no responses were gathered. In line with a narrative literature review around fifty articles were deemed relevant for use, these shall be presented in this order:

- Historical context of SM;
- The condition SM;

- The aetiology of SM;
- The characteristics, and maintenance of SM;
- The impact of SM;
- Co-morbidity and misdiagnosis;
- Role of the Educational Psychologist; and
- Research questions,

For further clarification please look at part three.

The historical context of SM

SM was first described in the literature by German physician Adolph Kussmaul, who most believed labelled the condition *Aphasia Voluntaria* or in English “voluntary inability to speak” (Driessen et al. 2020, pg. 331; Segal, 2003). However, it is thought that this is in fact a malapropism of the term *aphrasia voluntaria* meaning “voluntary absence of speech” which seems to be more conceivable (Driessen et al. 2020, pg. 331; Kussmaul, 1877). Kussmaul (1877) described a condition in which individuals will not speak in certain circumstances, despite having the ability to speak, also known as “absence of speech without disturbance of speech” (Driessen et al. 2020, pg. 331; Krysanski, 2003). In 1934 Tramer, following a case study of a seven-year-old boy, proposed a change of name for the condition to *elektiver Mutismus*, or *elective mutism*, in order to signify that children and adolescents with the condition will speak to certain individuals but not to others (Driessen et al. 2020, pg. 331; Segal, 2003). However, this name change was primarily chosen to signify his beliefs that individuals with this condition were electing not to speak (Krysanski, 2003). In 1980 elective mutism first appeared in the Diagnostic and Statistical Manual of Mental Disorders-III (DSM-III) within the subsection of other disorders of infancy, childhood or adolescence (Driessen et al., 2020; Khan & Rank, 2018). The families of individuals with the condition nevertheless protested that the term ‘elective’ implied that those individuals with the condition were choosing not to speak (Segal, 2003). The efforts of relatives of individuals with the condition and researchers resulted in a third name change in 1994 in the DSM-IV to *Selective Mutism* (Segal, 2003). The shift to SM was to emphasise that the individual with the condition is only mute in select contexts (Sharkey & McNicholas, 2008). However, it is important to note that the international classification of diseases-10 (ICD-10)

guidelines still refer to the condition as *elective mutism* within the section behavioural and emotional disorders with onset usually occurring in childhood (WHO, 1992). Finally, in 2013, SM was reclassified as an anxiety disorder, due to its extensive phenomenological and familial overlap with social anxiety disorder (SAD) (Stein et al., 2011). The reasoning behind this shift was primarily because anxiety was identified as a prominent feature of the condition, with many of the symptoms and behaviours of SM being anxiety related; with the finding that other childhood anxiety disorders contribute to the aetiology of SM; and because treatment of the condition is usually through the use of cognitive behavioural therapies or pharmacotherapy with selective serotonin reuptake inhibitors, similar to the treatment of anxiety (Kim, 2020). However, there is some disagreements on whether this was the correct move for the condition, with Kim (2020) suggesting that there is heterogeneity with the condition, where some forms of the condition may be more closely allied with the Autism Spectrum Disorder (ASD) as opposed to anxiety or specifically SAD.

The condition SM

SM is a rare, but for the most part severe, disorder of communication, which is characterised by persistent failure to speak where speech is typically expected (e.g. school) whilst speech appears to be typical in other situations (e.g. home) (Driessen et al., 2020; Remschmidt et al., 2001; Sharkey & McNicholas, 2008). The condition is associated with sensitivity with new people in new contexts and is usually, but not necessarily, diagnosed in childhood (Driessen et al., 2020; Segal, 2003). However, the patterns of not speaking can vary: some may not talk within the home, some may never talk outside of the home, some may whisper, some may talk to strangers and some may talk to a selected few, which further complicates the condition (Klein et al., 2013). Historically, SM was believed to be associated with oppositionality and was thought that one was electing not to speak, it has since been re-categorised as an anxiety-related condition (Khan & Renk, 2018). SM can be currently found within the DSM-V in the “anxiety disorders” section, where the criteria for the condition is that it *“should occur consistently in situations where there is an expectation for speech (such as educational, occupational or social settings); a child or adult is able to speak in other situations; the disorder lasts for more than a month (excluding the first month of a child’s school life); mutism is not better explained by a communication disorder, autism, schizophrenia or a psychotic disorder; and that there is no more*

apparent explanation for mutism such as a lack of knowledge or comfort with the spoken language in a given setting (e.g. if the child or adult has recently moved into a new culture” (American Psychiatric Association [APA], 2013, p.195). However, Forrester and Sutton (2016) in their book discuss how there are potential problems with this definition such as: SM can progress so much that the individual is no longer able to speak to anybody at all, SM is a common co-morbidity of ASD, and although children who move into a new culture do experience an adjustment period which frequently includes ‘mutism’ such an adjustment period can be a trigger for the onset of SM. The ICD-10 provides further guidelines for a diagnosis of *elective mutism* where the individual must meet these three criteria (WHO, 1992, p.278):

- “A normal, or near normal, level of language comprehension.
- A level of competence in language expression that is sufficient for social communication.
- Demonstrable evidence that the individual can and does speak normally or almost normally in some situations.”

The symptom profiles of both checklists describe individuals who are ‘selective’ with regards to when, where and with whom they speak to due to their experience of anxiety (Khan & Renk, 2018). Although children may not speak in particular social situations, they may however communicate non-verbally through nodding, pointing or pushing (Segal, 2003). Nevertheless, of note is that an individual with SM may talk in these social situations, if the fear of not talking is greater than their fear of talking (Johnson, 2020). The discrepancies across the diagnostic criteria and the rarity of the condition mean that prevalence rates are difficult to establish, the condition is probably underdiagnosed, and the prevalence rate is perhaps greater than is being recognised (around 1%) (Alpaslan et al., 2016; Khan & Renk, 2018). The age of onset for SM ranges from 2.7 years to 4.1 years, however it may not be recognisable until the individual is presented with the challenge of speaking in specific or novel social situations (e.g. when the child starts in school) which can lead to a delay between onset of the condition and time of referral (Henkin & Bar-Haim, 2015; Segal, 2003). The average age for referral and diagnosis therefore is generally between 5 and 7 years (Alpaslan et al., 2016). The onset of the condition appears to be slow and subtle, as opposed to sudden, with variability in the length of the disorder, with some individuals presenting symptoms for a few months whilst for others it could be

for a few years (Alpaslan et al., 2016; Mayworm et al., 2015). Incidence of SM tends to decrease with age, and the condition has reported good remission rates within young adulthood, however, it is theorised that the longer the condition goes untreated, the more difficult the recovery (Alpaslan et al., 2016; Mayworm et al., 2015). Furthermore, much like other internalised disorders, it is also believed that SM occurs twice as frequently in females as in males (Gaumon & Paquette, 2012; Segal, 2003). Previous research suggests that individuals whose families immigrate to a different country are more likely to be diagnosed with SM than the general population, despite the DSM-V criteria specifically stating, "*that there is no more apparent explanation for mutism such as a lack of knowledge or comfort with the spoken language in a given setting*" (APA, 2013, p. 195; Mayworm et al., 2015). A Canadian study found that immigrant children were 13 times more likely to be diagnosed with SM, whilst a study in the United States of America (USA) found that English as an Additional Language (EAL) pupils were more likely than their monolingual peers to gain a diagnosis of SM (Bradley & Sloman, 1975; Mayworm et al. 2015; Toppelberg et al, 2005). However, for an EAL child it can be hard to distinguish between an 'adjustment period' and SM. The 'adjustment period' allows the children to concentrate on comprehending and listening and is an adaptive period for an EAL child (Mayworm, et al. 2015). Despite the previous findings, neither the DSM-V nor any other diagnostic tool address the criteria for appropriateness of diagnoses for EAL children (Mayworm, et al. 2015). Which as Mayworm et al. (2015), Bradley and Sloman, (1975) Toppelberg et al. (2015) and Forrester and Sutton (2016) state can be problematic due to the arguments that individuals can be both an EAL and have SM.

The aetiology of SM

The cause of SM is largely unknown, although it has been described in the medical and psychological literature for years its aetiology is still not properly conceptualised (Henkin & Bar-Haim, 2015; Sharkey & McNicholas, 2008). Although Tramer, as early as 1934, suggested that there may be numerous factors that need to be considered to unravel the aetiology of SM; the underlying neural mechanisms have only recently been explored (Dreissen et al. 2020; Henkin & Bar-Haim, 2015). From the developmental psychopathology perspective, in order to create a complete picture of the child's difficulties, multiple perceptions on the aetiology of a condition

should be integrated (Mayworm et al. 2015). Therefore, it is thought that possibly familial (genetics and environment), developmental, neurobiological, psychodynamic and behavioural factors could contribute to the aetiology and presentation of SM within individuals (Dreissen et al. 2020).

i. Familial factors

Throughout the literature there has been mention of a familial component within the aetiology of SM. This has been suggested for several different reasons, one being that increased shyness, social phobias and public-speaking aversions have been associated within relatives of individuals with SM (Segal, 2003). Within Segal's (2003) paper they suggested that the SM concordance in their monozygotic female twin participants, coupled with their mother's fear of public speaking would be consistent with this specific reasoning for the familial factor of the condition. However, the researchers mentioned that there appeared to be a discordance among the severity signals of symptoms between the twins; this they said could highlight the significance that environmental factors may have on the genetically based tendencies (Segal, 2003). Black and Uhde (1995) found within their study a high prevalence of social phobia amongst family members of individuals with SM; with "avoidance of public speaking" being among the most common symptoms reported (Krysanski, 2003, pg.31). However, Krysanski (2003) mentioned that this may be that adults are in a more fortunate position to avoid uncomfortable speaking environments, therefore, the reluctance to speak behavioural symptom aspect of social phobia may be less apparent within adults than it is in children with SM. Furthermore, Kristensen and Torgersen (2002, p.350) found in their study that there was a high prevalence of social phobia and shyness amongst the parents of children with SM, which they mentioned indicated that SM is a "familial phenomenon". However, research has suggested that there is in fact not a direct genetic, but a direct environmental transmission of anxiety from parents to children (Eley et al., 2015; Khan & Renk, 2018). Khan and Renk (2018) further mention that as children learn to regulate their emotions through caregiver modelling and interactions, if their caregivers exhibit difficulty in regulation of their own anxiety, they may reinforce these behaviours in their children. Following this, with regards to attachment theory, children rely on attachment figures to determine if it is safe to explore the world, anxious parents may inadvertently communicate that the outside environment is

'unsafe' for them to explore (Bowlby, 1969; Bowlby, 1973; Khan & Renk, 2018). In terms of SM this may be why children feel unsafe in communication environments which are outside of their 'safe spaces' or in attachment theory terms their 'secure bases' (Bowlby, 1969; Khan & Renk, 2018). Additionally, studies have found that there is a persistent and strong bond of interdependence between mother and child, which could create a "symbiotic mutism" leading to SM (Remschmidt et al., 2001, p.285).

Another reason for the possible familial component in the aetiology of SM is the prevalence rates of communication deficits among families of individuals with SM (Sharkey & McNicholas, 2008). Some research has found that in around 50% of the cases mutism was present amongst other family members and others found 50% of the cases reported taciturnity amongst either the mother or the father (Remschmidt et al., 2001). Similarly, Sharkey and McNicholas (2008) highlighted the compounding factor that the environment has on the familial component.

Finally, an additional familial component that is mentioned within the literature is that children with SM are within "faulty" family relationships, which in turn give rise to the symptoms of mutism (Krysanski, 2003, p.32). With some researchers classifying the cause as a "neurotic relationship" between parents and the child which is characterised by "dependence and ambivalence coupled with an excessive need to control" (Subak et al., 1982, p.337; Krysanski, 2003). With the families of individuals with SM, being said to have a fear and distrust of the outside world and strangers, marital disharmony, language and cultural assimilation difficulties and intense attachments (Meyers, 1984; Krysanski, 2003). It is speculated that the "neurotic relationships" between families and the child are then carried over into the child's interactions with others (Krysanski, 2003, p.32). Dow et al. (1995) also mentioned that a possible cause of SM could be a reaction to trauma, such as, divorce, death of a loved one, abuse, life-threatening experiences, and even frequent moves (Krysanski, 2003, p.32). Research has suggested that frequent moves (both home and/or school) could be a potential risk for SM, following evidence that there was a higher incidence of household or school moves, amongst individuals with SM (Kristensen, 2000). Several studies have also reported a higher prevalence of SM amongst families who have immigrated (Cunningham et al., 2004). However, the link

between family dysfunction and SM has only been suggested through case reports, they have not been replicated within larger studies (Cunningham et al., 2004). Cunningham et al. (2004) found no differences in parenting strategies, economic resources, support networks or marital status of families of children with SM versus controls, although parents of individuals with SM mentioned that there were some disciplinary difficulties. Additionally, no differences within family dysfunction and parental depression were found between controls, similarly to Kristensen's (2001) finding of no differences between parents of children with SM and controls in terms of psychiatric disorders (Cunningham et al., 2004). Thus, Cunningham et al. (2004, p.1369) concluded that "the absence of structural and functional differences in families of children with SM and controls questions the generality of case reports linking SM to family dysfunction".

ii. Developmental

A developmental trajectory has been mentioned within the SM aetiology literature. One particular delay is that of speech and language development, However the research into this area is scant and mixed (Bergman & Gonzalez, 2019; Remschmidt et al., 2001; Steinhausen et al., 2006). Within some studies it appears as though children with SM have receptive language deficits, including but not limited to phonemic awareness and receptive vocabulary (Bergman & Gonzalez, 2019; Manassis et al., 2007). Whilst others have reportedly found average performance on receptive and cognitive language abilities, with the deficit (albeit subtle) lying within the expressive language skills (Bergman & Gonzalez, 2019; McInnes et al., 2004). Remschmidt et al. (2001) mentioned a meta-analysis (Poller 1989) of seven studies (Funke et al. 1978; Kolvin & Fundudis 1981; Kurth & Schweigert 1972; Popella 1960; Rösler 1981; Wergeland 1979; Wright 1968) which provided evidence that language development delay was present within nearly half of participants with SM (47%), with speech disturbances present within 38%. Andersson and Thomsen (1998) and Kristensen (2000) further confirmed these results, with Anderson and Thomsen finding a rating of nearly 50% in their participants for developmental language disorder (Remschmidt et al., 2001).

Another, suggested by Cohan et al. (2006), is a developmental trajectory whereby a child who experiences anxiety may have a heightened sensitivity to verbal

interactions with others due to a communication disorder, developmental immaturity or immigrant status, which may be triggered by an environmental stressor (such as new school entry). This then leads to a failure to speak in these settings despite having the ability to do so (Sharkey & McNicholas, 2008).

iii. Neurobiological

SM is now conceptualised as an anxiety disorder, this is in part due to the research into the links between SM and SADs such as social phobia (Sharkey & McNicholas, 2008). It is believed that another aetiological underpinning of SM could be that of an underlying neurodevelopmental vulnerability, this vulnerability is said to predispose the child to the development of SM (Sharkey & McNicholas, 2008).

In terms of anxiety disorder, Steinhausen et al. (2006, p. 751) noted that the similarities between anxiety disorders and SM are not simply restricted to environmental, temperamental and biological aetiologies, but that they also appear within clinical symptoms. (Bergman & Gonzalez, 2019). Bergman and Gonzalez (2019) suggest that the lack of speech in individuals with SM could be an avoidance mechanism, which serves the purpose of relieving or avoiding anxiety. Johnson and Wintgens (2001) suggest that it is an intense arousal of the sympathetic nervous system within novel situations during early childhood which leads to a reaction similar to that of freezing, this results in reduced interactions with feared stimuli, and subsequently shapes and habituates this avoidance behaviour in the form of inactivity and muteness (Golub et al., 2021). Young et al. (2012, p.525) found that there was less physiological arousal amongst children with SM during social interaction tasks, when compared to children with no diagnosis or children with SAD, despite evaluators rating them as more anxious, less socially effective, and more “impaired”. However, as some children with SM do not exhibit social anxiety in terms of their non-verbal social engagement, researchers have questioned if there is a link between SAD and SM, instead they suggest that opposed to anxiety to social situations it is specifically related to expressive language (Bergman & Gonzalez, 2019). Driessen et al. (2020) note that although there may be co-morbidity amongst SM and anxiety disorders, this does not imply that SM originates from this source. The researchers based this statement off the finding that 80% of children with a diagnosis of SM in their study had a comorbid diagnosis of anxiety disorder but

mentioned that it was unclear how the anxiety manifested in the remaining 20% of their participants which lacked this additional diagnosis (Driessen et al., 2020).

Other researchers argue that SM is a variant of social phobia, with 97% of the children in Black and Uhde's (1995, p.847) study being diagnosed with social phobia or avoidance disorder and 30% with "simple phobia" (Krysanski, 2003). Excessive social anxiety was noticed as a unanimous characteristic amongst these participants, with each participant also fitting the diagnosis for SM (Black & Uhde, 1995; Krysanski, 2003). This they mentioned along with the findings of high incidence rates amongst individuals with SM in families with social phobia, suggests that SM is a variant of social phobia (Black & Uhde, 1995; Wong, 2010). Johnson and Wintgens (2015) agree with these findings by suggesting that SM should be classified as a specific speech phobia, as they mention it is a panic reaction to specific situations which compels individuals to avoid them, this was suggested following advice from young individuals with the condition and their parents. However, these results have not been consistently found within the research. Yeganeh et al (2003) found only moderate levels of social anxiety in the self-reports of individuals with SM, this they said suggests that extreme social distress such as a social phobia may not fully explain SM (Wong, 2010). Melfsen et al. (2006) used the social phobia and anxiety inventory, to investigate social anxiety within different mental disorders. The findings suggest that SM cannot be a manifestation of social phobia, as children with SM scored lower overall compared to children with social phobia, if it were the case that it was a manifestation Melfsen et al. (2006) suggested it would fall within the same range (Wong, 2010). Furthermore, Melfsen et al. (2006) suggest the age of onset of individuals with SM and individuals with social phobia do not coincide (SM between 2.7 years to 4.1 years and social phobia being between 11 and 13 years), as it is thought that social phobia needs a certain degree of cognitive development to manifest (Wong, 2010). Wong (2010) also mentions that individuals with SM can 'outgrow' the disorder, however this is not possible with social phobia, signifying that SM may not be a variant of social phobia.

Another potential neurobiological basis of SM is that of a deficient auditory efferent feedback pathway (middle-ear acoustic reflex) (Bergman & Gonzalez, 2019). This theory suggests that auditory aberrations could interfere with a person's ability

to simultaneously process external sounds and speak, which creates an abnormal subjective experience of their own vocalisations, resulting in the individual with SM not wanting to talk in order to process what is being said, and due to the sensation they experience (Bergman & Gonzalez, 2019). However, this area has not been researched fully.

iv. Psychodynamic

From a psychodynamic perspective, SM is viewed as a manifestation of unresolved conflict (Krysanski, 2003). It is assumed that the individual has an oral and/or anal fixation and wishes to punish their parents through 'choosing' not to talk within certain situations (Krysanski, 2003). It is thought that the individual may be displacing anger toward a parent, regressing to a nonverbal stage of their development, or maintaining a family secret (Wong, 2010). Therefore, the mutism is viewed as a means to cope with anxiety, anger or as a means of punishing the parent (Krysanski, 2003). However, there appears to be little empirical data to support this perspective, therefore the psychodynamic view is currently losing validity (Wong, 2010).

v. Behavioural

Another lesser-known perspective is that of the behavioural theorists, who suggest that SM is a product of negatively reinforced learning patterns (Krysanski, 2003). Whereby the mutism is a learned strategy in which the individual manipulates the environment in response to social triggers, meaning that it is a product of the interaction between the individual and their environment (Wong, 2010; Krysanski, 2003). It is believed that the silence is a functional adaptive behaviour, which the environment helps to maintain (Krysanski, 2003). It is thought that the SM 'freezing' may be due to behavioural inhibition, whereby the sympathetic nervous system takes inhibitory control over the ability to speak and behaviour (Wong, 2010). Therefore, from this perspective it is deemed that SM is an "unconscious, language-based form of behavioural inhibition" (Wong, 2010, p. 28). Meaning that SM can be framed simply as a symptom of anxiety as opposed to being a consciously manipulative behaviour (Wong, 2010).

vi. *“Mental retardation” (Remschmidt et al., 2001, p.285)*

A lesser mentioned potential cause that has been cited in the literature is that of “mental retardation” now more commonly referred to as intellectual disability (Federal Registrar, 2013; Remschmidt et al., 2001, p. 285). Although Remschmidt et al. (2001) mention that for the most part intellectual functioning of individuals with SM is in the average or above average range, there are some studies who have reported the presence of an intellectual disability. Nonverbal IQ’s of below 70 have been observed by Reed (1963) in two of the four cases in their study, whereas cognitive deficits were present within two of the three subjects within Kupietz and Schwartz’s (1982) study (Remschmidt et al., 2001). Kolvin and Fundudis (1981) found that the SM participants had a lower mean nonverbal IQ compared to their typically developing control group, while intellectual disabilities were reported in two cases of SM in Klin and Volkmar’s (1993) study (Remschmidt et al., 2001). Finally, in one study recorded by Kumpulainen et al. (1998) it was found that a third of the children with SM were performing below average within school (Remschmidt et al., 2001). However, the studies reported here have mainly been case studies or small studies, therefore care must be taken when interpreting the link between intellectual disability and SM, as it is a finding that has not been replicated recently and within larger studies.

vii. *Trauma*

Finally, a further controversial explanation of the aetiology of SM is that of trauma. It is thought that SM could be a product of hospitalisation, trauma or major life events before the age of 9 (Remschmidt et al., 2001; Steinhausen et al., 2006). In Andersson and Thomsen (1998) a third of their sample had experienced a traumatic event during the development of their speech, with a higher incidence of movement of house or changes in school being found in Kristensen’s (2000) study, whilst Steinhausen and Juzi (1996) found that 31% of their SM sample had experienced a stressful event prior to the onset of SM (Cunningham et al., 2004). Omdal (2007) discussed how all informants in her study had described traumatic incidences within their childhood, with three of them being associated with the onset of their SM such as through change of school, war and birth of a sibling. However, Black and Uhde (1995) only identified significant early trauma in four of the thirty

participants, and amongst those four they found no temporal or causal relationship between abuse and onset of SM in any way. Further to this, Wong (2010) suggested that although there may be a connection between post-traumatic stress disorder and SM, it is not linked to the actual trauma, rather the connection simply highlights the common dissociative characteristics between each of the conditions.

This research suggests that the aetiology of SM is likely to be multifactorial, consequently there appears to be no one theoretical rationale which would be sufficient to explain SM (Khan & Renk, 2018). Therefore, as evidenced above and suggested by Steinhausen et al. (2006) a multi-dimensional model of SM appears to be the most appropriate explanation. Thus, due to this the development and trajectory of SM, may appear different for each individual (Mayworm et al. 2015).

The characteristics, and maintenance of SM

Very little previous research has focused solely on the characteristics of SM. What there is mainly focuses on the characteristics of the parents of children with SM or focuses on the characteristics associated with communication partners, the place of communication and activity as opposed to specific characteristics of the condition (Coiffman-Yoros, 2002; McHolm et al., 2005; Schwenck et al., 2021). McHolm et al. (2005) hypothesised that it is the communicative partner that has the most impact on the ability to speak in individuals with SM (Gensthaler et al., 2020). Whilst Schwenck et al. (2021, p.1) found that there were several factors such as the characteristics of the communicative partner (in particular “lack of distance”), unknown places and novel activities which can all be a trigger for the mutism. However, Segal (2003) acknowledged that although novel situations and people do produce anxiety for individuals with SM, there are certain times within developmental junctures where novelty may be essential to allow individuals to speak. It has been suggested that the majority of characteristics are connected to the condition’s aetiological factors, such as social anxiety, behavioural inhibition and a strong need for control (Schwenck et al., 2021).

i. Selective speech patterns and limited communication

As previously mentioned, SM is characterised by a consistent failure to speak in some situations despite typical verbal behaviour in others, signifying that the

condition does not fluctuate and is not mood dependent (Johnson & Wintgens, 2015; Segal, 2003). Previously it was believed that children with SM were simply just shy due to refusal of play and clinging to their mothers (Segal, 2003). However, this is not the case and patterns of communication can be varied for each individual, some children may be mute in all situations, whilst some children may speak at school, but not at home, for the majority of children with SM their mutism lies within the school (Sharkey & McNicholas, 2008; Bergman & Gonzalez, 2019). For this reason, parents are often left baffled by the dramatic difference in their children's behaviour at home to school, as parents report that individuals with SM appear to be excessively talkative within the home context (Bergman & Gonzalez, 2019; Segal, 2003). Johnson and Wintgens (2015) however, make reference to the fact that children with the condition are not always completely silent within the school environment. It is mentioned that although they may not speak directly to a teacher, they may speak in front of one, or they may even respond with "short or monotone utterances" but they "do not initiate or reciprocally respond when spoken to by others" (Johnson & Wintgens, pg. 62). For some children however, they will continue to interact outside of their 'comfort zone' through use of non-verbal gestures, facial expressions, nodding, monosyllabic utterances or pulling and pushing (Alpaslan et al., 2016; Krysanski, 2003; Schill et al., 1996). In fact, children and adolescents who are completely mute in various situations are in the minority, most individuals with the condition are able to communicate to a certain extent, such as to certain children or teachers, or in the playground (Schwenck et al., 2021). For others this muteness may even transfer to answering the telephone, where the twins in Segal's (2003) study would only talk on the phone to individuals they were familiar with. Previously it has been thought that this muteness develops due to anxiety, and as it is now classified as an anxiety disorder this would make sense (Johnson & Wintgens, 2001). This could be supported by Mary who mentioned in Oades and Patterson (2015, p. 148) "I don't have . . . much control over my ability to speak." However, one study which provided data on the psychophysiological assessment of symptomology demonstrated that this muteness could be an effective avoidance strategy, which is used to decrease emotional and physiological distress, as opposed to being too overwhelmed by anxiety to produce words (Young et al., 2012).

ii. Anxiety

Unlike in Young et al. (2012), a main component of the DSM-V and within other literature is the characteristic of anxiety (Diliberto & Kearney, 2016; Diliberto & Kearney, 2018; Omdal, 2007; Vecchio & Kearney, 2005). In one study a high percentage of participants with SM met the criteria for SAD (Vecchio & Kearney, 2005). Latent profile analyses of individuals with SM have suggested that there are three classes, all of which contain anxiety (Cohan et al., 2008). The three groups were anxious- mildly oppositional whereby they presented as having stubborn or controlling behaviour in anxiety-provoking situations, anxious-communication delayed, and exclusively anxious, they mentioned that these findings helped to confirm the presence of substantial anxiety in individuals with SM, but also with factors such as oppositionality present as well (Cohan et al., 2008; Diliberto & Kearney, 2018). Some have mentioned that children with SM, due to the anxiety, have difficulty adjusting to novel situations and subsequently express hostility, displeasure, or resentment to parents as a result (Diliberto & Kearney, 2016; Ford et al., 1998) Others, have mentioned that general features of irritability or negative affect are present among some youth with SM (Diliberto & Kearney, 2016; Gordon, 2001). However, in some studies anxiety could be seen as a secondary disorder due to the SM (Omdal, 2007). Linda mentioned that when she was younger, she would not characterise herself as anxious socially, however, as the years passed, and others did not understand her and bullied her for her SM she then began to withdraw within social situations (Omdal, 2007). Omdal (2007) also mentioned that this was common amongst others in the study.

iii. Clinical observations, Oppositionality and Perfectionism

Within clinical settings children with SM have often been described as “anxious, submissive, dependent, shy, timid, reticent, inhibited, fearful, withdrawn and compulsive” (Diliberto & Kearney, 2016, pg. 17; Sharkey & McNicholas, 2008; Krynski, 2003) which Diliberto and Kearney (2016) state may be due to the individual’s fear of gaining negative consequences for speaking. The research suggests that individuals with SM appear to have difficulties with social engagement and subsequently have difficulties with theory of mind, which researchers suggest impairs their social judgement of others’ intentions and thoughts; they cling to their

parents and then subsequently resist parental separation; avoid eye contact; and appear to 'freeze' when they are spoken to (Diliberto & Kearney, 2016; Schwenck et al., 2021; Sharkey & McNicholas, 2008). This freeze response is said to be a passive coping strategy which is expressed through motor and vocal inhibition (Diliberto & Kearney, 2016; Schwenck et al., 2021; Sharkey & McNicholas, 2008). Oppositional negative behaviour has also been suggested in the literature as a characteristic of SM (Remschmidt et al., 2001). Ford et al. (1998) remarked that parents reported their children as having oppositional behaviours within their study. Diliberto and Kearney (2018, p.551) commented how anxiety, oppositionality and inattention domains were present within their participants, they further observed through latent class analysis varying symptom profiles of SM, these they mentioned were "1) moderately anxious, oppositional and inattentive, 2) highly anxious, and moderately oppositional and inattentive, and 3) mildly to moderately anxious, and mildly oppositional and inattentive." With the second group being the most impaired of the three and the third group being the least, this they mentioned helped to confirm previous findings of oppositional profiles amongst individuals with SM (Diliberto & Kearney, 2018). However, within other research clinical-observers, not parents, reported oppositional behaviour (Wong, 2010). For this reason, researchers have warned against the overemphasising of the oppositional nature of the condition, as this, they say, lends itself to unwarranted premature interpretation, due to these characteristics not being present within all individuals with the condition (Wong, 2010). Other researchers have suggested that another characteristic that is present within individuals with the condition is that of perfectionism, this they mention is due to negative reinforcement (Schill et al., 1996). Observations within Schill et al.'s (1996) study appear to show that children with the condition were less likely to speak if given a specific demand to complete. Parents within Schwenck et al. (2021) would agree with this finding as they reported that mutism within their children was associated with challenging activities, other researchers (namely Vogel et al. [2019]) found that individuals with SM have an increased fear of mistakes.

iv. Communication disorders

The DSM-V criteria for SM states that children whose silence can be better accounted for by a communication disorder should be excluded from the diagnosis of

SM (Klein et al., 2013). Therefore, by definition, the language development of individuals with SM should be within the normal limits (Schill et al., 1996; Stein et al., 2011). However, within around 25% of cases there appears to be subtle expressive and/or receptive language problems (Stein et al., 2011). Within Klein et al.'s (2013) study 42% of participants displayed expressive narrative language deficits. Within a Norwegian study 50% of individuals with SM met diagnostic criteria for communication disorders (Rozenek et al., 2020). Furthermore, numerous studies have found difficulties in articulation and delayed speech in individuals with SM (Andersson & Thomsen 1998; Kristensen 2000; Remschmidt et al. 2001). Within Cohan et al.'s (2008) study 43.1% of the participants displayed poor receptive language and syntax abilities along with social anxiety, this, they mentioned, was the most impaired group when compared to an anxious-mildly oppositional group and an exclusively anxious group. Cohan et al. (2008) mentioned that these findings suggest that factors such as speech and language problems are often present within individuals with SM. Researchers have suggested that this may be what enhances anxiety within social situations, in those with SM, due to embarrassment related to miscommunication or imperfect speech (Manassis, 2007). This embarrassment was echoed within the participants in Oades and Patterson (2015, p. 145 and 147) who shared similar fears, Louise mentioned "I thought that my words would come out in a jumbled, nonsensical manner and my voice would be all choked and squeaky.", Emily mentioned "I would be judged, the words would come out wrong or my voice would sound strange or shaky, or that people wouldn't hear."

v. Abnormal auditory efferent activity

Another characteristic of SM that is infrequently mentioned in the literature is that of abnormal auditory efferent activity (Bar-Haim et al., 2004; Henkin & Bar-Haim, 2015; Muchnik et al., 2013). Results from Bar-Haim et al. (2004) indicated that abnormal auditory efferent activity was present within two thirds of the sample (of which there were 16), more specifically significant aberrations in the middle-ear acoustic reflex (MEAR) thresholds and reduced activity of afferents from the medial olivocochlear bundle (MOCB) reflex. Muchnik et al. (2013) further clarified this by finding 71% of their sample showed auditory efferent abnormalities that were due to aberrant MEAR and/or MOCB function. They concluded the MEAR and MOCB dysfunction could be related to auditory processing deficit, this they mention could mean that an individual with SM may have difficulty simultaneously coping with self-

vocalisation and incoming sounds, which subsequently causes a sub-conscious or conscious dilemma between choosing between speaking and/or listening in varying situations (Muchnik et al., 2013). MEAR dysfunction in particular can cause certain environmental sounds to become distorted or inexplicably noisy, which could be what causes the aversion to one's own voice in individuals with SM (Muchnik et al., 2013). This combination of listening difficulties and perceived social anxiety, they mention could be what leads the individual with SM to resolve the dilemma through avoidance of vocalisation (Muchnik et al., 2013). Henkin and Bar-Haim (2015) further explain why these auditory deficits have the impact that they do for children with SM, with specific relation to the environments where SM is most commonly present. It is mentioned that auditory environments, such as the playground or school, typically involve background noise, which they mentioned imposes high perceptual demands on the child with SM and auditory deficits (Henkin & Bar-Haim, 2015). This subsequently lends itself to being more prone to speech avoidance, as opposed to more personalised scenarios, such as home or in an assessment room, which are quieter, less demanding environments (Henkin & Bar-Haim, 2015). It is further mentioned that the adaptive significance assigned to the accurate processing of the auditory information in that context may also play a part in the ability to speak, such as, a child may find it easier to miss a few words when communicating with parents as opposed to answering a question in class (Henkin & Bar-Haim, 2015). Furthermore, it is speculated that the interaction between auditory deficits and shy, socially anxious and inhibited temperament could be what is affecting the communication of an individual with SM and a stranger (Henkin & Bar-Haim, 2015). It is thought that the whispering, distorted vocalisations and speech avoidance that is mentioned in the literature as characteristic of individuals with SM, could actually be due to these aberrations in efferent activity (Muchnik et al., 2013). However, the researchers mention that these aberrations in efferent activity are most likely not the primary determinant factor of SM in most individuals, but that for some it could be that increased socialisation could interact with psychological processes and aberrations in the auditory efferent system which in turn produces the clinical representation of SM, and with the co-morbidity between SM and social anxiety this could further aggravate symptoms and distort auditory input (Henkin & Bar-Haim, 2015, p. 90).

vi. SM within the EAL population

Interestingly, the literature suggests that there could perhaps be a different presentation of characteristics for individuals who are multi-lingual (Mayworm, et al., 2015; Toppelberg et al., 2005). Although the DSM-V criteria states that “there is no more apparent explanation for mutism such as a lack of knowledge or comfort with the spoken language in a given setting (e.g. if the child or adult has recently moved into a new culture)” (APA, 2013, p.195), researchers have provided when exceptions should be made. Toppelberg et al. (2005) mentioned that when the mutism becomes prolonged, severe and disproportionate to second language acquisition, this in turn warrants the diagnosis of SM in individuals who are bi-lingual. They refer to the fact that typically, children who learn a second language will not feel fully comfortable until 6 or more months, yet this they mention is unlikely to justify complete failure to speak (Toppelberg et al., 2005). Elizalde-Utnick (2007), Toppelberg et al. (2005) and Mayworm, et al. (2015) provide what they call the distinguishing factors between the “silent period” and SM. They mention that a bi-lingual child with SM will be mute in both languages, in a variety of settings and for substantial periods of time (Toppelberg et al., 2015, p.594). Whereas, other bi-lingual children that are within their “silent period”, will be only mute within one language, in only a couple of settings and for a short period of time (Toppelberg et al., 2015, p.594). Some researchers have suggested that the short period of time for the “silent period”, typically lasts less than 6 months, lasts longer the younger the child is and normally is present within younger children (3 to 8 years) (Mayworm, et al., 2015, p.194). However, it is important to mention that language acquisition is distinguished by two areas: Basic Interpersonal Skills (BICS) and Cognitive Academic Language Proficiency (CALP) (WLGA Strategic Migration Partnership, n.d.). BICS is the language that is used for social interaction and can generally take up to 2 years to acquire, it is also known as “context embedded communication”, the CALP involves more cognitively demanding language, required to access the curriculum in schools and can take 5-7 years to acquire, also known as “context reduced communication” (WLGA Strategic Migration Partnership, n.d.; Grigorenko, 2005, p.14). Therefore, care should be taken when trying to distinguish between the “silent period” and SM as it may well be that the individuals have not been exposed to the language in various settings and for a certain period of time in order for them to acquire their

BICS and CALP, meaning the silence may well be due to a lack of knowledge or comfort with the spoken language in a given setting despite it lasting for longer than 6 months (WLGA Strategic Migration Partnership, n.d.; Mayworm, et al., 2015, p.194).

vii. Diagnostic criterion suggestions

Johnson and Wintgens (2015) in their study proposed diagnostic criterion for SM, which starts with the DSM-V criteria such as (i) that it is a consistent failure to speak; (ii) that it lasts for longer than a month; and (iii) that it is not better explained by lack of knowledge of, or comfort with the spoken language. However, it then further expands upon the DSM-V criteria and adds further criterion such as (iv) the avoidance of or marked fear or anxiety within specific social situations, which is directly proportionate to the pressure or expectation of speech; (v) that individuals may communicate through gestures, nodding or shaking the head, making a noise or writing, monosyllabic, short or monotone utterances, or communicating through an altered voice or whisper in place of communicating via typical verbalisation; (vi) that the disturbance interferes with educational, occupational or social communication achievement; (vii) that the failure to speak is not better accounted for by stuttering or expressive language problems in communication disorders, social communication problems in ASD, oppositionality in Oppositional Defiant Disorder (ODD), fears of negative evaluation in SAD, and (viii) does not occur exclusively during the course of psychotic disorders such as pervasive development disorder and schizophrenia (Johnson & Wintgens, 2015, p.69, box 5). They further mention that provided individuals meet the criteria proposed above, that they may be diagnosed with SM in addition to alternative communication difficulties such as ASD, communication disorder or simply being multi-lingual individuals (Johnson & Wintgens, 2015). Although, this proposed set of criterion provides a more comprehensive guide to the characteristics of the condition for diagnostic means, it has yet to have been formally researched. Furthermore, some researchers have further provided evidence of uncharacteristic characteristics of SM such as facial expressivity and social popularity that still may dissuade correct diagnosis even with this more detailed approach, therefore there still appears to be more that needs to be done to expand definitions and concepts of this condition (Segal, 2003).

viii. Maintenance of SM

It appears social roles play an important part in the characteristics and maintenance of SM. Segal (2003, p. 483) noted that the twins within her study were able to speak to another child whilst in a waiting room, she remarked that when asked why they would not speak within the school they replied, “our friends like us as we are”. Furthermore, Segal (2003) noted that recovered speech typically occurs within novel places, not where the individuals with SM were once mute. Omdal (2007) recalled how individuals with SM, were determined to not speak simply due to others wanting them too, with one participant mentioning that talking would subsequently undermine her sense of self. Furthermore, four of the participants were highly aware of their behaviour limits and how others would react to these, Omdal (2007) mentioned that this was due to the bullying that they had endured. Schwenck et al. (2021, p. 7) mentioned that when an individual with SM assigns a person the role of a non-talking person, this person is then classified as “contaminated”, it then becomes harder for them to break this role of silence with the “contaminated” individual. This is shown through Emily in Oades and Patterson’s (2015, p.146) study where she remarks about speaking in front of people who had never heard her speak “I don’t know . . . it might have shocked them if they heard me talk, and it might have drawn attention to me”. Participants in Omdal (2007) echoed these views as they focused on their social role and identity as the ‘silent girl’, they mentioned that they did not think they could cope with the gained attention if they spoke. This attention from others, serves as a punisher and subsequently lends itself to reduced likelihood of talking in those settings in the future (Schill et al., 1996). It is then believed that the withholding of speech may result in a secondary change in the individual, which subsequently maintains the behaviour (Krysanski, 2003). Directives, requests, and task demands can be aversive to the individual with SM, SM is then negatively reinforced by the removal of these demands (Schill et al., 1996). The removal of these demands could be through allowing the child to communicate through other means, thereby reinforcing the mutism, or by others simply not asking the child to speak, reinforcing the mute behaviour (Krysanski, 2003). Observations of interactions have shown these to be the case, for example in one study it was found that the younger brother intervened when unfamiliar individuals posed a question to the child with SM (Schill et al., 1996). They mentioned that it was thought that the child relies on others to ‘save’ her from these

situations, yet when the brother was instructed not to speak for her, she was able to produce some verbalisations (Schill et al., 1996). Participants in another study mentioned that they felt that others would 'win' if they were to speak (Omdal, 2007). Some researchers believe that individuals with SM enter social situations silently in order to minimise humiliation and reduce anxiety (Manassis et al., 2007). Which researchers have suggested leads to a lack of arousal in social interaction tasks, which they suggest represents successful avoidance of their distressful situation (Young et al., 2012). Furthermore, adults who have recovered from the condition have mentioned that lack of speech was a self-protective response, as by refusing to speak, they perceived themselves as gaining control and protecting autonomy during situations that they experienced neglect, abuse or bullying (Omdal, 2007).

Finally, research has suggested that individuals with SM tend to have fewer episodes of joint attention during stressful structured tasks, this they insinuate could be another mechanism through which the condition of SM could be maintained (Nowakowski et al., 2011). Joint attention is important for socioemotional development, due to them being reliant on both social partners actively focusing on the same object, topic or event to share experience or provide information effectively (Nowakowski et al., 2011). The processes underlying joint attention creates opportunities for the learning of differing social skills such as problem solving, turn-taking, emotional regulation, and theory of mind (Charman et al., 2000; McEvoy et al., 1993; Mundy & Willoughby, 1996; Nowakowski et al., 2011; Sheinkopf et al., 2004). When individuals withdraw from interactions, especially during stressful structured tasks, opportunities for discussion and subsequent reduction of anticipatory negative thinking, as well as modelling of behaviours such as problem solving, coping mechanisms and emotional regulation are lost (Nowakowski et al., 2011, p. 87). This they suggest leads to individuals failing to develop the skills needed to cope within these difficult situations, therefore, suggesting they simply turn to withdrawal and/or avoidance, consequently resulting in the continued maintenance of their distress and subsequently their SM (Nowakowski et al., 2011).

The impact of SM

SM may impact individuals negatively in differing ways, SM has been related to rejection or difficulties with peers, school failure, aggravated intrafamilial

relationships and difficulties with overall psychological functioning (Henkin, & Bar-Haim, 2015; Mayworm et al., 2015; Muchnik et al., 2013). As SM discourages opportunities for social interaction this could not only restrict involvement in everyday activities with other children; dissuade individuals from attending school or completing academic work; but it could also potentially lead to a developmental delay of appropriate language skills (Diliberto & Kearney, 2016; Krysanski et al., 2003).

Individuals with SM have been noted in the literature to often be victimised by their peers, some believe that this is due to their shy and inhibited presentation (Cunningham et al., 2004). However, Kumpulainen et al. (1998) only reported that 5% of children with SM were bullied and 16% were rejected by peers. Further research has shown that there are higher rates of victimisation within community samples without SM when compared to individuals with SM (Cunningham et al., 2004; Wolke et al., 2000). Cunningham et al. (2004) in their study also found that children with SM were less likely to be victimised by peers, they suggested that children with SM who tend to be victimised are those with submissive traits, parents and teachers within the study did not rate children with SM as more submissive than controls therefore they noted that this was why their rates may be lower. They also noted that children with SM who were rated as more assertive by both parents and teachers were less likely to be victimised in school (Cunningham et al., 2004). However, they did find that children with SM who had higher ODD scores were more likely to be victimised by peers (Cunningham et al., 2004). Nevertheless, in personal accounts of individuals with the condition bullying and victimisation is usually mentioned. Within Stambaugh and Sood (2014) they mention that Seung-Hui Cho experienced 'teasing' during his high-school years, specifically relating to his refusal to speak and interact with others as opposed to his appearance or ethnicity. Within Omdal (2007) it is mentioned that Elisabeth and Sarah were bullied by peers because of their fears, Omdal mentions that this bullying strengthened their need to remain in control and thus maintain the identity as the girls who do not speak.

Impairments within school functioning has also been noted in the literature (Krysanski, 2003). It is believed that as individuals with SM often do not speak within a school setting, this can impede on the student's ability to fully benefit from their

education (Mayworm et al., 2015). Within McInnes et al. (2004, p.304) they found that children with SM produced shorter narratives than children with social phobia, despite them showing normal nonverbal cognitive and receptive language abilities, they suggested that this subtle expressive language deficit could be what impacts upon academic performance for individuals with the condition. Others have suggested that individuals with SM may experience impairment within the classroom setting since failure to speak in front of or to teachers makes it difficult for these individuals to perform certain academic tasks (e.g., reading out loud) and for the teachers to be able to assess the individual's readiness for school, educational level and learning (Bergman & Gonzalez, 2019). One study reported that 32% of individuals with SM were performing below their grade level, unfortunately they did not include a control group within their study, however, another study which included control groups found that teachers often rate academic performance of individuals with SM significantly lower than their peers (Bergman et al., 2002; Kumpulainen et al., 1998). Yet, Cunningham et al. (2004) believe that teachers may inadvertently underestimate the academic skills of individuals with SM because they may not speak in the classroom. In their study they found that contrary to previous research, the maths and reading scores of children with SM did not differ from controls, but they did highlight that teachers did tend to rate reading skills as being lower in the participants with SM, somewhat supporting the theories suggested above by Bergman and Gonzalez (2019; Cunningham et al., 2004).

However, these perceived negative impacts of SM may only be negative within Western Cultures. Stambaugh and Sood (2014) within their book remarked about how in Korean society calmness is a valued feature and noisiness is frowned upon, they mention how being a 'quiet child' is perceived as more scholarly and is a highly desired attribute within Korea. Therefore, it is important to be mindful that the negatives remarked upon above may not be viewed within the same light within other cultures.

Co-morbidity and misdiagnosis

There are several co-morbid characteristics that have been identified within the SM literature. These are including, but not limited to anxiety, language disorders,

developmental delay, motor difficulties, chromosomal diagnoses, ODD and ASD (Alpaslan et al. 2016).

Due to SM residing in the anxiety section of the DSM-V criteria, it should come as no surprise that SM has been associated with a wide variety of child psychiatric conditions (Sharkey & McNicholas, 2008). Several studies have reported associations between SM and enuresis and encopresis (Kolvin & Fundudis, 1981; Kristensen, 2000; Sharkey & McNicholas, 2008). Other psychiatric conditions linked with SM include, generalised anxiety disorder (GAD), social phobia, agrophobia, separation anxiety, obsessive-compulsive disorder (OCD), schizophrenia, catatonia, ODD and depression (Chavira et al., 2007; Cunningham et al., 2004; Diliberto & Kearney, 2016; Driessen et al., 2020; Golub et al., 2021; Johnson & Wintgens, 2015; Khan & Renk, 2018; Klein et al., 2013; Kristensen, 2000; Kristensen & Torgersen, 2002; Krysanski, 2003; Manassis et al., 2003; Omdal, 2007; Remschmidt et al., 2001; Rozenek et al., 2020; Schwenck et al., 2019; Schwenck et al., 2021; Sharkey & McNicholas, 2008; Stein et al., 2011; Young et al., 2012). In one study with 54 participants diagnosed with SM, 46.3% of patients also met criteria for an anxiety disorder, 68% were diagnosed with social phobia, 32% with separation anxiety, 13% with GAD and 13% with specific phobia (Kristensen, 2000, Rozenek et al., 2020). In another, 70 participants diagnosed with SM all met diagnostic criteria for social phobia, whilst 40% met criteria for separation anxiety disorder (Chavira et al., 2007; Rozenek et al., 2020). A meta-analysis of 22 studies which comprised of data on 837 children with SM, found that social phobia (SAD) was present within 69% of children, which the authors deemed to be the most commonly diagnosed co-morbid disorder, specific phobia was present in 19%, separation anxiety disorder in 18%, GAD in 6% and OCD in 6% (Driessen et al., 2020). Whilst ODD has been found to be in as many as 29% of youths with SM (Diliberto & Kearney, 2016; Yeganeh et al., 2006).

i. Developmental

In addition to co-morbid anxiety conditions, Neurodevelopmental delay has also been associated with SM in terms of both language and motor function (Diliberto & Kearney, 2016; Oerbeck & Kristensen, 2008). Developmental delay has been reported in the literature as being present within a range from 46.3%-68.5% of individuals with SM, however limited comparable studies have been conducted

(Krysanski, 2003; Rozenek et al., 2020). It is thought that children with SM may be able to conceal their developmental delay through their silence, which in turn creates a maladaptive coping strategy (Alpaslan et al., 2016).

The dominant developmental disorder present within Kristensen (2000) is that of co-morbid communication difficulties which have been reportedly found within half of children with SM; with speech and language delay reportedly present within 68.5% of individuals (Diliberto & Kearney, 2016; Khan & Rank, 2008; Klein et al., 2013; Kristensen & Torgersen, 2002; Krysanski, 2003; Manassis et al., 2013; Nowakowski et al., 2011; Remschmidt et al., 2001; Rozenek et al., 2020; Sharkey & McNicholas, 2008). These communication difficulties include articulation problems, speech delays, stuttering and expressive and/or receptive language problems (Henkin & Bar-Haim, 2015; Khan & Rank, 2008; Manassis et al., 2007). Some researchers believe that the delays and difficulties within language development could contribute to the development of the condition (Oerbeck & Kristensen, 2008; Sharkey & McNicholas, 2008). Whilst others believe that it is in fact the teasing that individuals may face from peers who are deemed to have appropriate language skills, that then ignites the pattern of avoidance and resultant mutism (Alpaslan et al., 2016).

Research has suggested that the most prevalent language disorder in SM is articulation disorder, this, some researchers have said, suggests a reflection of motor problems residing as a co-morbidity of SM (Kristensen, 2000; Kristensen & Oerbeck, 2006). Motor delay has been consistently reported in SM despite few studies including a direct assessment, with some researchers suggesting that it may be subtle motor impairment and not anxiety alone, which causes withdrawal from social situations for some with the condition (Kolvin & Fundudis, 1981; Kristensen & Oerbeck, 2006).

ii. Chromosomal abnormalities

Chromosomal abnormalities have also been reported within the SM literature, as there have been several case reports of SM in children with chromosomal abnormalities, with the most pervasive abnormality being Cornelia de Lange syndrome whereby 40% of verbal participants were shown to have signs of SM (Mervis et al., 2015; Moss et al., 2016; Sharkey & McNicholas, 2008). The other abnormalities that have been noted are Fragile X Syndrome, Chromosome 18 Abnormality, Williams Syndrome and learning disabilities (Moss et al, 2016; Sharkey

& McNicholas, 2008). It has also been noted that ASD has been found to occur more frequently within SM families (Sharkey & McNicholas, 2008).

iii. ASD

Despite the diagnostic criteria's wording "not better explained by ... autism", ASD does also coexist with SM (APA, 2013, p. 195; Cengher et al., 2021; Klein-Tasman & Mervis, 2018; Klin et al., 2005; Krynski, 2003; Moss et al, 2016; Muris & Ollendick, 2021; Wright et al., 1994). Individuals with a diagnosis of ASD, have social-communicative deficits that can often cause difficulties navigating social situations (Cengher et al., 2021). It is thought individuals with ASD develop higher degrees of anxiety than their neurotypical peers, due to these difficulties (Cengher et al., 2021). This anxiety then can be associated with SM, and research suggests that over 60% of individuals with SM also have a diagnosis of ASD or developmental disability (Cengher et al., 2021). Co-occurrence of SM and Asperger syndrome has been noted by a variety of researchers (Anderson & Thomsen, 1998; Kopp & Gillberg, 1997; Kristensen, 2000; Rozenek et al., 2020) whilst Kopp and Gillberg (1997) found that one in five children with SM within their study met criteria for ASD. Steffenburg et al. (2018) evaluated the rate of ASD amongst 97 children with a diagnosis of SM; 63% of the children met diagnostic criteria for ASD (4% Asperger Syndrome, 30% atypical autism/pervasive developmental disorder not otherwise specified, 29% autism), with the next 20% presenting with subclinical symptoms of autism, which the researchers mentioned still had an impact on their everyday lives (Steffenburg et al., 2018, pg. 1165; Rozenek et al., 2020). However, although there was a large sample within this study, the study was based on retrospective chart reviews, providing some uncertainty regarding the quality of the data obtained (Steffenburg et al., 2018).

a) Pathophysiological

A shared pathophysiology has been mentioned in the literature between SM and ASD, due to the above-mentioned similarity of features such as the impairment in social communication and interaction (Stein et al., 2011). Stein et al. (2011) hypothesised that there may be a possible genetic association between SM and ASD within the contactin-associated protein-like 2 (CNTNAP2) gene. The

researchers argued that due to this gene being specifically implicated with the developmental language delay component in ASD and since SM is characterised by failure to speak and is often associated with developmental language problems, that this may suggest a partially shared aetiology for ASD and SM through CNTNAP2 and its subsequent influence on language development which they suggest may underlie both conditions (Stein et al., 2011). Through a family-based association study, 99 nuclear families which included 106 children with SM were recruited and supplied salivary DNA (Stein et al., 2011). The researchers found through their family-based sample that CNTNAP2 is also associated with risk for SM, however they mention that the risk allele that is present within SM (rs2710102) is the non-risk allele for ASD and specific language impairments (Stein et al., 2011). Therefore, they suggest that the findings do suggest a partially shared aetiology between ASD and SM but that there needs to be more research to understand which aspects of the conditions are influenced by CNTNAP2 (Stein et al., 2011). They further mention that due to a lack of previous research in this area it is too premature to make strong inferences about the nature of the relationship between ASD and SM based on the association with CNTNAP2 (Stein et al., 2011). SM and ASD have also been hypothesised to be genetically associated with 7q11.23 duplication syndrome (Dup7) (Mervis et al., 2015; Klein-Tasman & Mervis, 2018). Mervis et al. (2015) found that 29% of children with Dup7 in their sample met criteria for SM, whilst 33.3% met criteria for ASD, they mentioned that conducting genotype/phenotype studies of this nature can be an effective opportunity to understand the contribution of these genes to common disorders, such as SM and ASD, which affect the general population. Furthermore, altered MOCB function has also been reported within ASD (Henkin & Bar-Haim, 2015). Within SM it is thought that altered MOCB could be the reason for the inability to talk in some settings when compared to others, as it causes children to choose between speaking and listening in varying situations, similarly within ASD it is thought that MOCB dysfunction underlies hypersensitivity to sound and poor speech perception in background noise (Henkin & Bar-Haim, 2015; Muchnik et al., 2013).

b) Importance of the link between ASD and SM

Suzuki et al. (2020) used the Selective Mutism Questionnaire-Revised (SMQ-R) and the Autism Spectrum Quotient (AQ) with teachers of typically developing children (TD), children with SM and children with ASD in the USA. They found that the children with SM scored significantly higher than the other children in the SMQ-R, however, in the AQ, both the children with SM and ASD scored significantly higher than the TD, but no discernible difference was observed between the two (Suzuki et al., 2020). Suzuki et al. (2020) mentioned that these findings suggest that many children with SM are likely to show ASD traits, yet not necessarily have the condition. They further mention that children within their study with SM and showing ASD traits do not possess particular behavioural traits of ASD but rather have a more general presentation (Suzuki et al., 2020). However, they do mention that although they can conclude that children with SM are likely to display a tendency to ASD, they found no correlation between the degree of SM and the tendency to ASD (Suzuki et al., 2020). Therefore, they state that it is important to measure the state of SM and ASD on independent scales before considering specific strategies to support individuals with SM. Cengher et al. (2021) echoes this statement as they found that the individuals in their study with a dual diagnosis were not only more prone to language delays but also had a higher proportion of borderline IQ compared to children with a single diagnosis of SM. They further speculate that due to these factors, individuals diagnosed with both SM and ASD may be more resistant to treatment (Cengher et al., 2021). The Selective Mutism Information and Research Association (SMIRA) are keen to have dual diagnoses of ASD and SM for this reason, as they suggest it is important to treat the anxiety side first through programmes, stimulus shaping and graduated exposure before implementing the interventions for ASD (Caroll, 2021).

iv. Misdiagnosis

As there is limited research into specific characteristics of SM and through a lack of a clear diagnostic criteria this has subsequently led itself to the problem of misdiagnosis (Driessen et al., 2020; Gensthaler et al., 2020). Steffenburg et al. (2018) found that the children in their study with SM and co-morbid ASD had a higher age at diagnosis for their SM, suggesting that the ASD may have been

masking the SM. Other research in this area has shown that there are a high percentage of children and young people who have been misdiagnosed as having different disorders such as ASD when they have SM (Caroll, 2021; Schwartz & Shipon-Blum, 2005; Spiro, 2021). Schwartz and Shipon-Blum (2005, p.30) report that children with SM are often misdiagnosed with shyness, ASD, oromotor dyspraxia or ODD, this they mention causes valuable time to be lost during “therapeutic misadventures”. Their main concern being that if diagnosed early and given appropriate management the cardinal symptom within SM can be cured, however this is less likely to be the case if treatment is delayed after the age of seven (Schwartz & Shipon-Blum, 2005). Professionals have suggested that due to the similar presenting symptoms of SM and ASD, such as lack of eye contact, lack of speech, lack of communication and appearance of ‘shutting down’, it can be difficult to understand the difference (Caroll, 2021; Spiro, 2021). Spiro (2021) suggests that professionals when approaching a diagnosis between SM and ASD should make the distinction between a performance deficit or a skills deficit (Spiro, 2021). It is thought that children with SM have a performance deficit as they have the ability to speak but simply cannot demonstrate it in every setting, whereas children with ASD have a skills deficit, so are unable to demonstrate certain skills regardless of the setting (Spiro, 2021). Spiro (2021) shares how professionals may distinguish between ASD and SM, through looking for this consistency across situations, as children with SM will usually be quite social and are often described as being chatterboxes within some settings, whereas ASD is a pervasive condition, therefore, the behaviours will be apparent across all settings (Caroll, 2021). Lawler (n.d.) in her personal report shares how being misdiagnosed as having ASD inhibited the actual treatment of SM from starting, which she suggests is likely to be common among children and young people like her. A lack of or a delay in intervention for children and young people with SM is likely to have a detrimental long-term impact on their social development, as SM is a condition that can have optimal treatment outcomes (Cline & Baldwin, 1998; Dean, 2012; Sharkey & McNicholas, 2008; Zakszeski & DuPaul, 2017). For example, within one follow-up study of 41 participants, 39% of participants showed a complete remission, with 29% showing a remarkable improvement (Remschmidt et al., 2001). Sharkey and McNicholas (2008) shared how mutism impacts on the social adjustment of individuals with SM at a crucial stage of development, which if it persists may cause long-term difficulties in terms of academic achievement and peer

interaction, regardless of whether there is an associated co-morbidity. SMIRA have suggested that misdiagnosis of ASD could potentially be harmful for an individual with SM (Caroll, 2021). This is due to the types of treatment used for the condition, for ASD interventions rely on making expectations clear e.g., writing a social story explaining the importance of greeting a teacher, as it is assumed that individuals with ASD do not know that they should do this (Caroll, 2021). For an individual with SM however, they are aware of what is socially expected of them, they want nothing more than to be able to do that, but they are not in a position to be able to do it, this then leads to further anxious and inhibited behaviour (Caroll, 2021). Caroll (2021) mentioned that the more expectation that is 'piled' on an individual with SM, the more they will feel misunderstood, which in turn will reinforce the anxiety that triggers the 'shut down' response. Khan & Renk (2018) further support this through their observation of Jasper, who appeared to regress in progress any time he felt, pressured, pushed or flooded by others.

Currently there is a lack of methodologically strong and psychometrically sound measures of characteristics of SM, which may be impacting on the rate of misdiagnosis (Bergman et al. 2008). Without access to these measures, previous diagnoses and research have relied on peripheral symptoms or subjective measurements which researchers have suggested could be problematic (Bergman et al. 2008).

Role of the Educational Psychologist

Educational psychologists (EPs) work with children, young people and young adults in both educational and early years settings, regarding problems that may hinder their chance of learning (British Psychology Society [BPS], 2021). There are five main areas of an EPs work: consultation, training, assessment, intervention, and research; which are carried out at four levels (i) individual level, (ii) group level, (iii) whole school level and, (iv) Local authority level (Boyle and Lauchlan, 2009, pg.72). Essentially the EPs role is to use psychology to promote positive outcomes within education (Cline, et al, 2015). One important area of EP practice is to help vulnerable groups of children, young people and young adults overcome inequality in attainment and achievement (Education Scotland, 2019). The National Foundation for Educational Research (NFER; 2019) define vulnerable groups in schools as: learners with special educational needs; looked after children; children and young

people living in poverty; excluded pupils and those at risk of exclusion; pupils with behaviour and attendance issues; Gypsy, Roma and Traveller pupils; Asylum seekers, refugees and new migrants; young carers; young offenders; young people with mental health issues and medical needs; young people not in education, employment or training; and teenage parents.

As mentioned above one such vulnerable group are learners with special educational needs (SEN), which SM can often be conceptualised as (Boyes Turner, n.d.). It has been suggested that on average an EP will encounter one child with SM every five years, yet with the rise of immigration within the UK this is likely to increase; due to the incidence rates of SM being higher within this population (Cleave, 2009; Cline & Baldwin, 1998; Dean, 2012; Forrester & Sutton, 2016; Mayworm, et al. 2015). SM is a condition that has a negative impact on children and young people's ability to engage with learning and social activities, however currently due to lack of knowledge and of standardised diagnostic measures, SM is often ascertained quite late (Gensthaler et al., 2020; Kryszanski, 2003; Zakszeski & DuPaul, 2017). Research has suggested that teachers who have an individual with SM in their class often experience a variety of emotions due to this such as helplessness, frustration, bewilderment and even anger (Cleave, 2009; Cline & Baldwin, 1994). Cleave (2009) suggests that these feelings, coupled with the likelihood that they have not come across an individual with SM before, may be what leads these teachers to seek support from agencies such as the Educational Psychology Service. When teachers are seeking advice from professionals on SM, the literature stresses the importance of professionals exploring SM with both parents and school (Cleave, 2009; Cline & Baldwin, 1994; Dow et al., 1995). EPs are well-placed to help with these concerns due to the consultative nature of their role and their unique systemic approach of working within the whole system of the child (Ashton & Roberts, 2006; Boyle and Lauchlan, 2009). Through consultations with both home and school there is opportunity to clarify exactly what is happening, gather understanding of family history and gain comparisons between settings, with the aim of developing hypotheses (Cleave, 2009; Macready, 1997). Not only that but through using systemic thinking within consultation, the EP has the ability to help individuals reflect, reframe and reconstruct 'problems' from being individualised to interpersonal; due to the literature suggesting that teachers may harbour negative feelings about children with SM, possibly construing them as defiant, this may be a

powerful tool through which possibilities for change can be developed and teachers can feel heard (Cleave, 2009; Cline & Baldwin, 1998; Fox, 2009; Gameson et al., 2003). Johnson (2020) has shared how EPs are in the position to make the diagnosis of SM, if they regard themselves as a diagnostic practitioner. However, in order to elicit testable hypotheses and perhaps diagnose, it is important for EPs to have an understanding of the causes of SM, yet the evidence of misdiagnosis suggests that perhaps there may be something missing to help aide the transition from information gathering to generating hypotheses (Cleave, 2009; Driessen et al., 2020; Gensthaler et al., 2020).

Research questions

As the *health and care professions council* (HCPC) requires EPs to “work within the limits of your knowledge and skills” (HCPC, 2018, paragraph 3) it is perhaps unjust to place an EP in the position of working with a child with SM if they are not knowledgeable on the condition. Yet, despite the new classification of SM as an anxiety disorder the DSM -V criteria of SM has not been changed to incorporate more specific characterisations, some researchers have hypothesised that this may be due to a lack of systemic research in the area (Driessen et al., 2020).

Therefore, this research seeks to investigate whether the characteristics observed by Johnson (2017) a speech and language therapist who is an expert in this area and is commonly referred to in the literature, are present within individuals with SM and examine if this checklist of characteristics could then be used to benefit EP’s hypothesis building. More specifically, the views of parents/carers and EPs will be sought to answer the following research questions:

- Are the characteristics observed by Johnson ([2017] a speech and language therapist specialising in SM) present within individuals with SM from the perspectives of parents of children with SM?
- Will awareness of these characteristics be beneficial in helping EPs elicit testable hypotheses?

Chapter Summary

The research questions have been generated as a response to the gap in the research, specifically specific characteristics of SM and lack of EP research into the

condition. Currently there is a lack of methodologically strong and psychometrically sound measures of characteristics of SM, which may be impacting on the rate of misdiagnosis (Bergman et al. 2008). Without access to these measures, previous diagnoses and research have relied on peripheral symptoms or subjective measurements which researchers have suggested could be problematic (Bergman et al. 2008). Previous checklists such as the SMQ-R, although useful, concentrate on the frequency of speech in differing settings (school, home/family and social situations) and do not delve into specific characteristics of the condition (Bergman, 2021; Suzuki et al., 2020). Unlike Johnson's (2017) list of diagnostic features that are unique to SM. However, as Johnson's (2017) checklist has not been subjected to critical review through research, it was deemed important to research whether the characteristics observed by Johnson (2017) are present within individuals with SM through the perspectives of their parents. Furthermore, as stated above the HCPC requires EPs to "work within the limits of your knowledge and skills" (HCPC, 2018, paragraph 3) yet despite this there appears to be very little research from the profession on the condition. Of what there is Cleave (2009) discusses the importance of EPs understanding the causes of SM in order to enable EPs to ensure that all relevant information is discussed and, in turn, elicit testable hypotheses. Yet, the evidence of misdiagnosis suggests that there may possibly be something missing to help aide this transition from information gathering to generating hypotheses. Therefore, it was believed that researching whether having awareness of the characteristics of SM could be beneficial in helping EPs elicit testable hypotheses, was important. In turn it is hoped that this would not only possibly help limit misdiagnoses but also add to the very limited research within the profession on the condition. Pages 59-64 describe the methodology employed to explore the research questions.

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“It’s the fact they’re no trouble to anybody. That’s the problem, isn’t it?”: An exploration of the characteristics of Selective Mutism and their applicability for the role of the Educational Psychologist.

Part 2: The empirical paper

Word count: 8,091

Abstract

Selective Mutism (SM) is a rare anxiety condition that affects 1 in 140 children (NHS, 2019) and is characterised by “a consistent failure to speak in specific social situations in which there is an expectation for speaking (e.g. school) despite speaking in other situations’ (e.g. home)” (Zakszeski & DuPaul, 2017, p.1). The lack of clear diagnostic criteria for SM and the perceived association between SM and Autism Spectrum Disorder (ASD) has leant itself to problems of misdiagnosis (Forrester & Sutton, 2015; Kopp & Gillberg, 1997). The purpose of this research was to investigate whether the characteristics observed by Johnson (2017), a speech and language therapist specialising in SM, are present within individuals with SM and see if a checklist of characteristics could be used to benefit Educational Psychologists’ (EPs) hypothesis building, using a mixed-methods approach. In total forty-six parental questionnaires were completed and analysed using descriptive statistics and three EPs participated in a focus group that was video recorded, transcribed and analysed using reflexive thematic analysis (Braun & Clarke, 2021a). The results suggest that there is a high probability that most of the characteristics observed by Johnson (2017) are present within SM and that a checklist of characteristics may be beneficial for aiding EPs hypothesis building, especially if it includes features of the condition, but that a checklist alone may not be enough.

Introduction

'She's given up talking don't say a word, even in the classroom not a dickie bird. Unlike other children she's seen and never heard' (McCartney, 2001).

For some children this song lyric may ring true, especially if they have Selective Mutism (SM). Although apprehension around talking is a common phenomenon amongst children and young people, it is far less common for this cautious behaviour to manifest into refusal to speak (Baldwin & Cline, 1991; Black & Ude, 1995; Cleave, 2009). SM is a rare anxiety condition that affects 1 in 140 children (NHS, 2019) and is characterised by “a consistent failure to speak in specific social situations in which there is an expectation for speaking (e.g., school) despite speaking in other situations (e.g. home)” (Zakszeski & DuPaul, 2017, p.1). This failure to speak is not attributable to a lack of comfort or knowledge with the language spoken or better explained by a communication disorder or Autism Spectrum Disorder (ASD) (Oerbeck, 2020; American Psychiatric Association, APA, 2013). However, there is some controversy around the diagnostic criteria of SM. Forrester and Sutton (2015) have discussed that in some extreme cases the mutism can progress so that some children and young people may not be able to speak at all. It has also been noted that although children who do find themselves in a new culture do experience an adjustment period which frequently includes ‘mutism’; such an adjustment period can be a trigger for the onset of SM (Forrester & Sutton, 2015). Yet, one of the main controversies regarding the diagnostic criteria is around ASD. Specifically, that ASD is a common comorbidity of SM, yet the diagnostic criteria’s wording “*not better explained by... autism*” may be perceived as misleading (APA, 2013, p. 195; Forrester & Sutton, 2015).

Kopp and Gillberg (1997) found that one in five children with SM within their study met criteria for ASD. Suzuki et al. (2020) found that many children with SM also have ASD traits present. Whilst Stein et al. (2011) found a partially shared aetiology (single nucleotide polymorphism rs2710102 which is found in the gene contactin-associated protein-like 2 [CNTNAP2]) between ASD and SM. The lack of clear diagnostic criteria and this perceived association between SM and ASD has led itself to problems of misdiagnosis. Steffenburg et al. (2018) found that the children in their study with SM and co-morbid ASD had a higher age at diagnosis for their SM. Other research in this area has shown that there are a high percentage of

children and young people who have been misdiagnosed as having different disorders such as ASD when they actually have SM (Caroll, 2021; Schwartz & Shipon-Blum, 2005; Spiro, 2021). Lawler (n.d.) in her personal report shares how being misdiagnosed as having ASD inhibited the actual treatment of SM from starting. She suggests that this is likely to be common among children and young people like her. A lack of, or a delay in, intervention for children and young people with SM is likely to have a detrimental long-term impact on their social development (Cline & Baldwin, 1998; Dean, 2012; Sharkey & McNicholas, 2008). Currently there is a lack of methodologically strong and psychometrically sound measures of characteristics of SM, which may be impacting on the rate of misdiagnosis (Bergman et al. 2008). Without access to these measures, previous diagnoses and research have relied on peripheral symptoms or subjective measurements which can be problematic (Bergman et al. 2008). Therefore, it is hoped that through this research a SM checklist could be created to provide professionals a clearer set of hypotheses, in order to minimise the problems seen here of providing inappropriate interventions.

SM is not the remit of any one professional group, which leads to inevitable delays in the management of the condition (Keen et al, 2008). As research suggests that SM can have a negative impact on the child's ability to engage with learning and social activities, then it would suggest that it is within the remit of the Educational Psychologist (EP) to be knowledgeable of this condition and work with it (Zakszeski & DuPaul, 2017). Currently on average it is estimated that an EP is likely to encounter one child with SM every five years (Cleave, 2009). With the rise of immigration within the UK this is likely to increase; as the incidence rates of SM is higher within this population (Cleave, 2009; Cline & Baldwin, 1998; Dean, 2012; Forrester & Sutton, 2016; Mayworm, et al. 2015). Cleave (2009) discusses the importance of having an understanding of the causes of SM in order to enable EPs to ensure that all relevant information is discussed and, in turn, elicit testable hypotheses. Yet, the evidence of misdiagnosis suggests that there may possibly be something missing to help aide this transition from information gathering to generating hypotheses. As the *Health and Care Professions Council* (HCPC) requires EPs to "work within the limits of your knowledge and skills" (HCPC, 2018, paragraph 3) it is perhaps unjust to place an EP in the position of working with a child with SM if they are not knowledgeable on the condition, therefore having a

checklist that they may be able to refer to could potentially help develop their knowledge (HCPC, 2018).

The purpose of this research is to investigate whether the characteristics observed by Johnson (2017), a speech and language therapist specialising in SM, over decades of work in this area are present within individuals with SM. The project also aims to examine if Johnson's (2017) checklist of characteristics could then be used to benefit EPs hypothesis building, when they are working with children and young people with these presenting needs in order to minimise the delay for intervention.

Therefore, this research explored the following research questions:

- Are the characteristics observed by Johnson (2017) present within individuals with SM from the perspectives of parents of children with SM?
- Will awareness of these characteristics be beneficial in helping EPs elicit testable hypotheses?

Researcher's position

The researcher was interested in this research for the following reasons:

- They have always had an interest in differing conditions, how they may impact individuals, how they present, what does the label mean and how diagnoses are made. This may in part be due to the researchers experience of gaining and having a diagnosis.
- During their first year of training to be an EP the researcher was given a case to research SM and create an information sheet. From this the researcher was able to see first-hand how the condition not only affects individuals but also the lack of research into the condition, especially EP research into the condition. Therefore, the researcher felt it important to try and add to this limited pool.
- Following training, delivered by Johnson (2020) there was mention of limited research specifically into specific characteristics of SM, which due to the research on misdiagnoses alarmed the researcher. Coupled with the evidence of SM having high remission rates, the researcher became keen to explore this area further.

- The researcher is aware of their position as a Trainee Educational Psychologist and the unique circumstance this provides for not only research but also EP practice. Therefore, the researcher wanted to use this privilege to research an under-researched yet debilitating condition.

Methods

Methodological theory

The final findings in this study are based on data analysis of the results of both the questionnaire of parents and the focus group of EPs. This followed a pragmatic parallel mixed-methods design, whereby the quantitative and qualitative aspects are performed independently, with the results converging in the overall interpretation, selected to increase the quality of the results (Mertens, 2014; Goutaudier et al., 2011; Schoonenboom & Johnson, 2017). Comparing the quantitative and qualitative data, through triangulation, helps to enrich the researcher's ability to draw conclusions about the perceptions of both sets of participants (Mertens, 2014). This will take a critical realist perspective, whereby the stance is that there is a discernible world that is independent of our knowledge yet access to this world is often mediated by our perceptual and theoretical lenses (Mingers et al. 2013). Table 1 shows two other paradigms that the researcher could have focused on. The table shows their epistemological, ontological and methodological stances in relation to critical realism, the table helped the researcher decide on their perspective for this study. Critical realism has been said to circumvent the problems related to paradigm 'switching' referring to the fact that some researchers believe that the qualitative and quantitative paradigms are so different that they cannot be merged, whereas critical realism believes that methods should be chosen through the research problem, with the important aspect being how the quantitative and qualitative methods are used, rather than if they are compatible (McEvoy & Richards, 2006, pg.79). By using the statistics from a critical realist perspective it should provide deeper levels of explanation and understanding to what is in the questionnaire data (McEvoy & Richards, 2006). By using Thematic Analysis (TA), in a critical realist perspective the researcher can acknowledge the ways individuals make meaning of their experience, as well as the ways in which the broader social context may affect those meanings, whilst retaining focus on the reality of the material (Braun & Clarke, 2006). Using the critical realist perspective is essential for a focus group exploring individuals' knowledge and views of SM and exploring how an SM checklist could be helpful. Therefore, it is important that reality is discernible through the research process whilst also being mindful that their meanings may be mediated by socio-cultural connotations.

For the quantitative aspect the researcher collected perceptions in the form of a questionnaire (Appendix A). For this, as ordinal data was collected, descriptive statistics were used for the analysis (Sullivan & Artino, 2013).

For the qualitative aspect, the researcher conducted a video-recorded focus group using Microsoft Teams. This was analysed using TA which is focused on developing themes and codes which are informed by the unique standpoint of the researcher (Braun & Clarke, 2021a; Smith, 2015). It has been stated that TA has been widely used within mixed-methods research (Braun & Clarke, 2021b). Braun and Clarke (2021b) mention that to have good use of reflexive TA within mixed-methods research, there is need for a clear value base, which the researcher believes this study has justified above. Therefore, it seemed appropriate to use this analysis.

Paradigm	Ontology (Reality)	Epistemology (Knowledge)	Methodology
Positivism	The world consists of universal laws.	Knowledge is produced in objective ways.	Quantitative approaches (surveys and experiments)
Constructivism	Irrealist, “the knower makes the world” (Bunge, 2001, p. 13010).	Knowledge production is fallible and theory-dependent, sometimes theory-determined.	Qualitative approaches (phenomenology, grounded theory, case study and narrative)
Critical realism	Real, there is a discernible world.	Knowledge production is fallible and theory-dependent, but not theory-determined.	Mixed-methods

Table 1. Research paradigms, views and methodology (Bunge, 2001; Creswell, 2009; Fryer, 2020; Mingers et al., 2013, Olsen, 2007)

Participants

Part 1- Parent’s perceptions of the characteristics of SM

Parents of children who have a diagnosis of SM, from several Facebook groups, were included in the current study. The questionnaire was attached onto a Facebook post in SM specific groups. All questionnaires were completed on Qualtrics (Qualtrics, 2005) within four months of them being placed on Facebook.

Inclusion criteria were that all participants that were recruited were parents or carers for children or young people with a diagnosis of SM. Sixty-two participants completed the consent section for the questionnaire, fifteen participants did not have a child with a diagnosis of SM and one participant did not finish the questionnaire, this left forty-six participants in total who completed the questionnaires.

Part 2- EP's perceptions qualitative

Using purposive sampling, EPs were recruited via invitation (Appendix B) that was sent via EPNET, a popular mailing list for EPs and other educational professionals. Inclusion criteria were that all participants that were recruited were practicing EPs. Smith (2015) states that for a doctoral research study there should be between three-to-six participants for a focus group. Originally four EPs emailed to express interest in participating in the focus group, unfortunately due to time commitments only three EPs participated in the focus group.

Measures

Part 1- Parent's perceptions of the characteristics of SM

A 15-item questionnaire (with a further four questions for demographics) was created from Johnson's (2017) observations of the characteristics of SM. Answers were rated on a 6-point Likert scale (ranging from 1= Always to 6= Not Relevant), with the final question asking if the questionnaire was easy to understand and providing a space for participants to give feedback.

Part 2- EP's perceptions qualitative

Data was collected via one video recorded focus group conducted in February 2022. The focus group followed a semi-structured format that was formulated following the completion of questionnaires. The researcher used the interview question sheet (Appendix C), with prompt questions, to explore the EP's perceptions of SM and whether a checklist would be beneficial to their practice.

Procedure

Part 1- Parent's perceptions of the characteristics of SM

The research questions were answered firstly by a parental questionnaire. A gatekeeper letter was sent to the administrators of various SM Facebook pages to enquire if the researcher could recruit through their pages (Appendix D). The questionnaires were made available online via Qualtrics, an online survey tool. The

participants were asked to first read an information sheet, tick a consent form and answer a screening question (does your child have a diagnosis of SM?) before commencing with the rest of the questionnaire. A debrief sheet was attached as the last page of the questionnaire (Appendix A). Materials used were the online platform (Qualtrics) and the questionnaire questions (which have been devised from Johnson's [2017] observations from practice [Appendix A]).

Part 2- EP's perceptions qualitative

The research questions were subsequently answered by an EP focus group. The focus group took place online via Microsoft Teams due to the Covid-19 pandemic. Once the participants had emailed to express a desire to be involved, they were emailed an information sheet and consent form and were asked to sign a consent form before arranging a preferred video conferencing method for all involved. Once informed consent had been collected the focus group took place and lasted around one hour, another trainee sat in on the focus groups and acted as a second facilitator as suggested by Robson (2015) in order to note who was speaking, note non-verbal interaction and also give feedback on the researcher's performance. Materials used were the online platform (Microsoft teams) and the interview questions sheet (Appendix C). Following the focus group, the participants were sent a debrief form via email (Appendix E).

Data Analysis

Part 1- Parent's perceptions of the characteristics of SM

Data was recorded and analysed using Qualtrics (Qualtrics, 2005). A descriptive analysis was undertaken to examine differences in mode scores for each question and graphs were produced for some in order to visually show interesting distributions. Mode was chosen as the preferred method due to Boone and Boone (2012) stating that for ordinal data the mode is the correct choice of statistical procedure.

Part 2- EP's perceptions qualitative

Primarily the TA for this piece of research involved working from a "bottom up" perspective where the codes were developed through reviewing what was in the data; identifying meaning at the surface level and describing the explicit meaning of the data, otherwise known as an inductive, semantic and descriptive approach (Braun & Clarke, 2013, p.178; Smith, 2015). This was chosen as this research is

interested in the perceptions of EPs on a specific condition, therefore it is imperative that the researcher stayed as close as possible to the meaning in the data for it to be a true representation of the participants reality. After the focus group had been conducted the videorecording was transcribed by the researcher. The coding schedule was produced from the transcripts (Appendix F). The coding consisted of codes, themes and subthemes, where the theme captured the overall common recurring pattern which was presented across the dataset, the themes described the different aspects of the pattern, with the subtheme existing beneath the umbrella of the overall theme (CND, n.d.). Appendix G offers a step by step run through of examples of the six phases of TA delineated by Braun and Clarke (2006; 2021a) following the structure implemented by Buzanko (2016). Braun and Clarke (2006; 2013; 2021a), Guest et al. (2012) and Smith (2015) were used as guidance for the write up of the analysis. Extracts of transcripts were taken for informative parts of the focus group, to further the understanding of the meanings behind the codes and themes.

Ethical Consideration

Ethical aspects of the quantitative aspects of this research focussed on:

The online questionnaire included information about the project and consent was given with an explicit tick box before being able to answer the questionnaire. Online questionnaires were completed using the Qualtrics software, with a debrief form at the end of the questionnaire. No identifying information was requested, and information was confidential. Anonymous responses were emailed to the researcher via a secure server.

Ethical aspects of the qualitative aspect of this research focussed on:

The focus group recording, and any personal details were kept on a password protected computer with anonymous information being retained for an unknown period indefinitely by Cardiff University, the recording was deleted in March 2022. Any identifiable information has been anonymised and pseudonyms were used. Whilst a virtual focus group cannot be considered to be confidential, the participants were reminded at the start of the focus group of the importance of confidentiality and to not mention what has been said within the focus group to others. Participants were reminded that only the researcher will have access to the video recording of the focus group. The names of EPs are not be disclosed to the wider audience (including

the local authority staff). Participants of the focus group were asked to read the consent form and provide a signature before the focus group could commence. Practices were put in place to mitigate any potential risks, such as: all participants were provided with an appropriate debrief form at the end of the interview; contact details of both the supervisor of the project and the ethics committee were provided to all participants and participants were reminded of their right to withdraw from the study.

Results

Quantitative Analysis

For the quantitative aspect, mode values and visualisations were used. To illustrate the quantitative findings a table will be presented with question number, questions and mode values for each score, followed by one graph picked to display interesting patterns in the data. For demographics, please see table 7 for total scores of questions, please see table 8.

Participants scored always for the following questions.

Question Number	Question	N=
1	Is your child only able to talk freely to certain people? e.g. you and others that they feel comfortable with or in other words people who would be in their 'comfort zone'.	32
2	Does your child follow a noticeable pattern of 'failure to talk' which has lasted for at least one month (or two months if it's within a new setting e.g. just moved schools).	36
3	Does your child stop talking to someone in their 'comfort zone' if they know that someone that is not within their 'comfort zone' is in the room and/or is able to hear them? E.g. your child may speak to you in an empty waiting room but will stop when someone comes into the room or your child may talk to their friend in the house but not at school where other children could hear them speak.	29
4	Does your child show a big difference between: Talking and interacting (smiling/laughing) freely with people in their 'comfort zone' and avoidance, non-verbal communication (e.g. nodding), silence or strained not typical communication (e.g. one word answers that may not fit with the context) with people not in their 'comfort zone'.	33

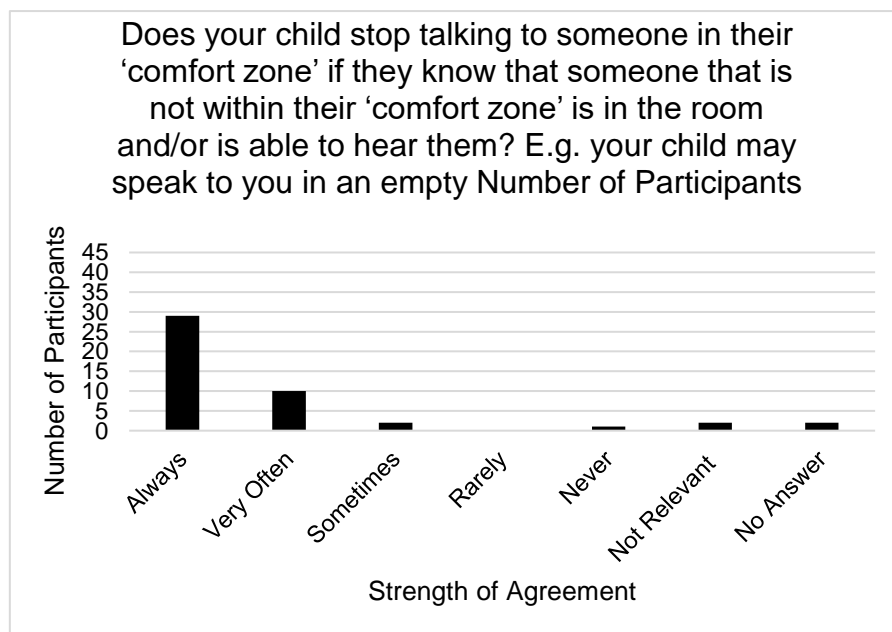


Fig. 1 Number of Participants for question 3.

Participants scored very often for the following questions.

Question Number	Question	N=
5	Does your child 'freeze' (their body gets rigid and they have a fixed facial expression that can sometimes be mistaken for a smirk) when someone outside of their 'comfort zone' is near, even though they were relaxed just before the person entered?	22
8	Does your child prefer to use non-verbal communication (e.g. nodding) and alternative means of communication (e.g. drawing/writing) with, or in front of, people outside of their 'comfort zone', even if that makes them look different from others around them?	17

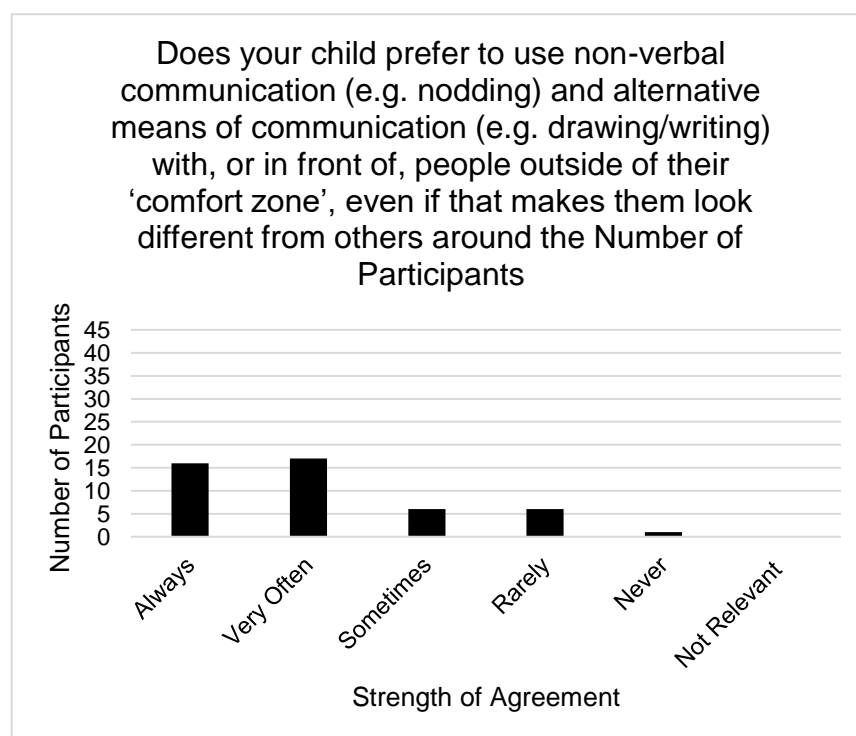


Fig 2. Number of Participants for question 8.

Participants scored sometimes for the following questions.

Table 4. Questions where the majority of participants scored sometimes		
Question Number	Question	N=
10	Does your child try and avoid situations where they fear they will be expected to talk? E.g. avoiding going to a family members house who always asks them questions or expects them to say please and thank you by asking to stay at home, dawdling or making a mess.	15
11	Does your child opt for silence? E.g. decides in advance that they won't talk, making no attempt to speak to those outside of their 'comfort zone' or by letting you know that they have no intention to talk?	12

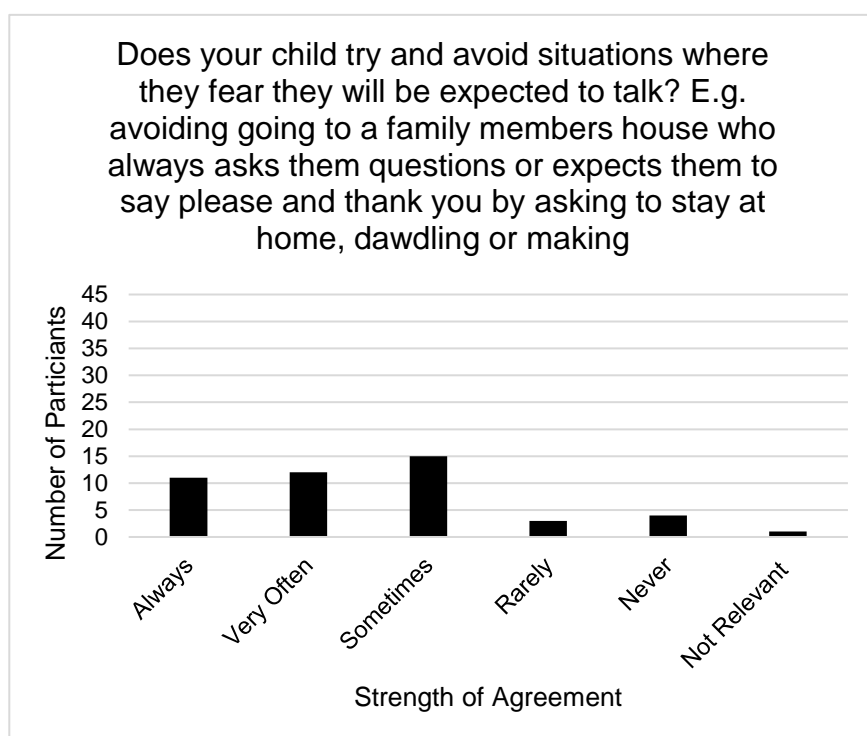


Fig 3. Number of Participants for question 10.

Participants scored rarely for the following question.

Table 5. Questions where the majority of participants scored rarely		
Question Number	Question	N=
13	Is your child able to answer questions if the conversation was initiated by someone outside of their 'comfort zone', but, they appear to have a 'frozen' facial expression, or a rigid, quiet, whispered or distorted voice?	15



Fig 4. Number of Participants for question 13.

Participants scored never for the following questions.

Table 6. Questions where the majority of participants scored never		
Question Number	Question	N=
6	Does your child complain that they want to talk but their voice just gets stuck in their throat?	12
7	Does your child say that when they try and speak they get a rapid heart-rate, shortness of breath and/or a tightness in their chest?	13
9	Does your child ever deny talking, stop talking and/or reject praise for talking, because they felt that this would lead to people expecting them to talk more because of it? (This is not the same as denying talking because you would get into trouble for talking).	17
12	Is your child able to initiate conversations with people outside of their 'comfort zone'?	32
14	Has your child ever started to panic, had a meltdown or avoided further contact after talking?	16

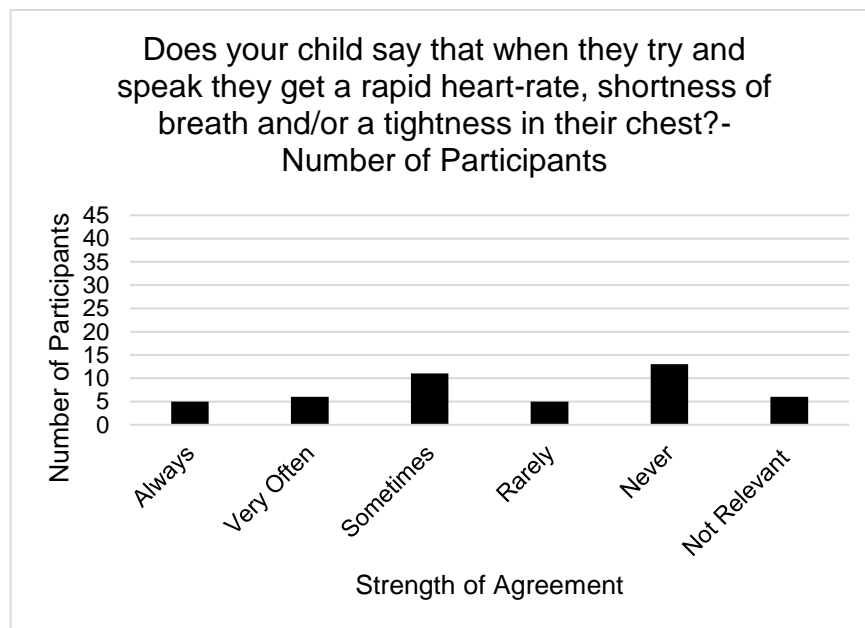


Fig 5. Number of Participants for question 7

Finally, question 15 asked participants if the questionnaire was easy to understand, participants who answered no were asked to provide feedback. Eight participants answered no to this question. For the majority of participants, they remarked that question 9 did not have complete answers and that some of the questions were 'wordy' meaning they needed to be re-read, causing them to worry they may have misunderstood them, particularly the questions with examples. Question 13 (19 to the participants) was mentioned as being confusing for one participant in particular. For other participants their main concern was the wording of the questions, with one suggesting that mention of a 'comfort zone' is too simplified and that it is about the people who the child is comfortable speaking to which is more relevant, however they remarked that if the child were to see the individuals out of context, then this can result in the child not speaking. Another participant mentioned that perhaps the wording could have been more considerate by stating that the children do not opt, choose or decide not to talk and do not prefer to nod sign and gesture, it is that they do not have a choice in the manner. Lastly, it was mentioned by one participant that some of the questions have more than one variable, assume an answer and could be quite leading, they provided the example of 'what if my child was able to answer questions from someone outside their comfort zone but without a distorted voice etc.'

Table 7. Demographics	
Participants Nationality	
Nationality	Number of Participants
British	19
South African	1
Welsh	1
English	1
German	1
White/Caucasian	3
American	13
Italian and English	1
Canadian/US Dual	1
Portuguese	1
Dutch	1
Polish	1
No Nationality Mentioned	2
Child's Gender Identity	
Gender Identity	Number of Participants
Male	11
Female	33
Non-Binary/Third Gender	1
Prefer not to say	1
Does the child speak more than one language e.g. bi-lingual or trilingual?	
Strength of agreement	Number of Participants
Yes	8
No	38

Table 8. Participant scores

Is your child only able to talk freely to certain people? e.g. you and others that they feel comfortable with or in other words people who would be in their 'comfort zone'

Strength of Agreement	Number of Participants
Always	32
Very Often	13
Sometimes	1
Rarely	0
Never	0
Not Relevant	0

Does your child follow a noticeable pattern of 'failure to talk' which has lasted for at least one month (or two months if it's within a new setting e.g. just moved schools).

Strength of Agreement	Number of Participants
Always	36
Very Often	0
Sometimes	3
Rarely	0
Never	1
Not Relevant	0
Most of the time	5
About half the time	1

Does your child stop talking to someone in their 'comfort zone' if they know that someone that is not within their 'comfort zone' is in the room and/or is able to hear them? E.g. your child may speak to you in an empty

Strength of Agreement	Number of Participants
Always	29
Very Often	10
Sometimes	2
Rarely	0
Never	1
Not Relevant	2
No Answer	2

Does your child show a big difference between: Talking and interacting	
Strength of Agreement	Number of Participants
Always	33
Very Often	11
Sometimes	1
Rarely	0
Never	0
Not Relevant	0
No Answer	1
Does your child 'freeze' (their body gets rigid and they have a fixed facial expression that can sometimes be mistaken for a smirk) when someone outside of their 'comfort zone' is near, even though they were relaxed just before the person entered?-	
Strength of Agreement	Number of Participants
Always	12
Very Often	22
Sometimes	9
Rarely	3
Never	0
Not Relevant	0
Does your child complain that they want to talk but their voice just gets stuck in their throat?-	
Strength of Agreement	Number of Participants
Always	5
Very Often	7
Sometimes	10
Rarely	8
Never	12
Not Relevant	4
Does your child say that when they try and speak they get a rapid heart-rate, shortness of breath and/or a tightness in their chest?-	
Strength of Agreement	Number of Participants
Always	5
Very Often	6
Sometimes	11
Rarely	5
Never	13
Not Relevant	6

Does your child prefer to use non-verbal communication (e.g. nodding) and alternative means of communication (e.g. drawing/writing) with, or in front of, people outside of their 'comfort zone', even if that makes them look different from others around them?-

Strength of Agreement	Number of Participants
Always	16
Very Often	17
Sometimes	6
Rarely	6
Never	1
Not Relevant	0

Does your child ever deny talking, stop talking and/or reject praise for talking, because they felt that this would lead to people expecting them to talk more because of it? (This is not the same as denying talking because you would get into trouble for talking).-

Strength of Agreement	Number of Participants
Always	2
Very Often	9
Sometimes	10
Rarely	4
Never	17
Not Relevant	4

Does your child try and avoid situations where they fear they will be expected to talk? E.g. avoiding going to a family members house who always asks them questions or expects them to say please and thank you by asking to stay at home, dawdling or making a mess.-

Strength of Agreement	Number of Participants
Always	11
Very Often	12
Sometimes	15
Rarely	3
Never	4
Not Relevant	1

Does your child opt for silence? E.g. decides in advance that they won't talk, making no attempt to speak to those outside of their 'comfort zone' or by letting you know that they have no intention to talk?	
Strength of Agreement	Number of Participants
Always	2
Very Often	8
Sometimes	12
Rarely	11
Never	10
Not Relevant	3
Is your child able to initiate conversations with people outside of their 'comfort zone'?	
Strength of Agreement	Number of Participants
Always	0
Very Often	0
Sometimes	1
Rarely	13
Never	32
Not Relevant	0
Is your child able to answer questions if the conversation was initiated by someone outside of their 'comfort zone', but, they appear to have a 'frozen' facial expression, or a rigid, quiet, whispered or distorted voice?	
Strength of Agreement	Number of Participants
Always	2
Very Often	7
Sometimes	10
Rarely	15
Never	12
Not Relevant	0
Has your child ever started to panic, had a meltdown or avoided further contact after talking?	
Strength of Agreement	Number of Participants
Always	0
Very Often	6
Sometimes	15
Rarely	6
Never	16
Not Relevant	3

Qualitative Analysis

For the qualitative aspect of this research two main themes from the focus group that related directly to the purposes of this study, were evident: (1) Role of the Educational Psychologist; and (2) ‘The five Ps’ formulation approach (the British Psychological society, 2019). Subthemes that were emergent shall be used to further explore the findings of the two main themes, please see figure 6 and figure 7 for a visual of these.

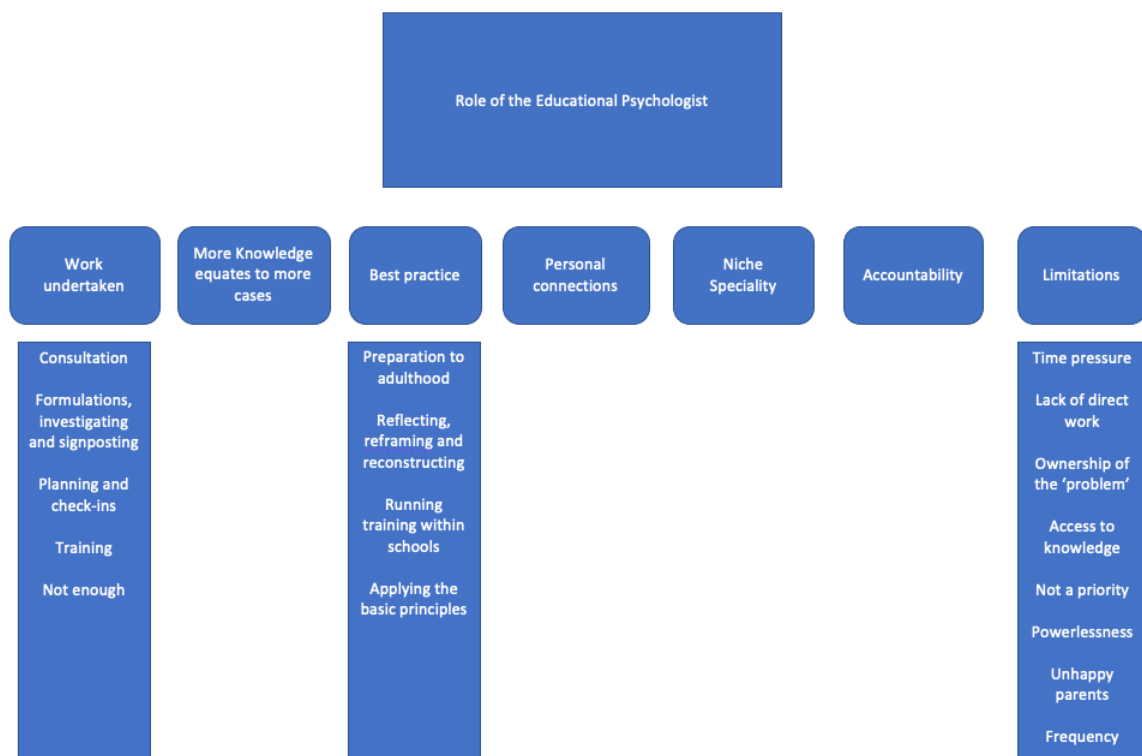


Fig 6. Visual of the theme role of the educational psychologist.

(1) Role of the Educational Psychologist

Research suggests that SM is within the remit of the EP (Cleave, 2009; Education Scotland, 2019). Therefore, it was important to explore what EPs thought their role with SM was and how they have worked with the condition. In terms of subthemes that were emergent, EPs' perceptions of the role of the EP within SM appeared to be centred around: the work undertaken, that more knowledge equates to more cases, sharing best practice within their work, their personal connections

with the condition, how it may be a potential niche speciality, accountability, and the limitations.

(1.1) Work undertaken

Throughout the focus group the work undertaken by EPs when working with children and young people with SM were discussed. The predominant amount of work undertaken centred around consultation:

“but it tends to be in a more consultation sort of role um and I think that’s probably quite typical for educational psychologists generally”- ppt2

But there was also mention of formulations, investigating and signposting:

“I think I get as far as a bit of investigating and formulating and signposting”- ppt1

Planning and check-ins:

“if they need a more sort of intensive intervention helping them plan what that’s going to look like and and sort of doing a kind of monitoring and checking in sort of role”- ppt2

And training for schools, paediatricians and speech and language therapists

etc.:

“but we’ve also done training for. Uhm, I I do training for schools there is also. The community paedics being trained. Uhm. And uh, the speech therapist, have been trained”- ppt 3

There was, however, an overwhelming sense that the work being undertaken was not enough:

“And I was so aghast at the fact that I'd been trained as an educational psychologist. Um But you know, I don't even remember if selective mutism was mentioned on the course. Um I felt quite angry about it, not just for my son, but for all the other people. You know, I had had people consult me previously about selective mutism, and I'd I'd sort of, you know, and done the same thing I'd said. Oh yes, you know, lower the pressure and. Look at these resources. But it's not enough.”—ppt 3

(1.2) *Knowledge equates to more cases*

There was a sense throughout the focus group that it seemed as though having more knowledge of the condition meant that there was an increase in the number of SM cases that were brought to the attention of EPs.

“sometimes I've only heard about them because I've mentioned my own personal interest in selective mutism, and then at the SENCo go. Oh well, we've got two at the moment. And it's my goodness. If I hadn't even mentioned the subject, he wouldn't have naturally thought to discuss this with me.”- ppt 2

From the above quote it also seems that had the EP not expressed interest in the condition due to the knowledge they had gained then it was highly unlikely that these cases would have even been mentioned.

(1.3) *Best practice*

During the focus group, the group members shared best practice advice for working with schools and the condition. This included using the preparation to adulthood materials:

“What's helped with that actually is the preparation to adulthood materials (nodding from the group), which I quote an awful lot in secondary schools. Um when I'm in there and they're saying, well, you know, yes, she doesn't talk but. She's OK and friend talks for her and then I can look at the preparation for adulthood materials and say, well, OK, but can she order herself something in a cafe? Can she go to the doctor and explain what's wrong with her? Can she do a job interview? can she, you know, get on the train and say I need a ticket for such and such? And then they kind of you can see the penny drop and they go oh, actually, that could be a problem. So I think that's been really helpful.”-ppt3

Reflecting, reframing, and reconstructing the constructs that individuals may have held around the condition:

“Now that you've explained this, you know when you explain it, I always explain it in relation to spiders. Um 'cause somebody will say, you know, well, they don't look very anxious. They play perfectly happily with their friend and I'll say, you know who here's got a spider phobia. And there's always somebody and I'll say, well, you don't look particularly anxious. And they say, well, there's not a spider here. And I say, well, you know, being expected to speak by an adult is the spider in this child situation. So as long as no, there's not an adult expecting them to speak. They they look for, they probably looked fine. Um and that seems to, you know, really help them to understand how it can be. That a child can be talking in one situation and unable to speak in another and it not be a choice.”-ppt 3

Running training within the schools themselves:

“we used to run light training where people could come from any school. And you know, we'd run it centrally. Um I think it's more effective to run it actually in the school though, so I I find it's better for the whole staff to know.”—ppt 3

And applying the basic principles of SM in other areas of the role:

“my ability to apply that those basic principles about anxiety, about small steps and um you know, reduction of pressure. But opportunities, you know, not not taking all pressure away but giving opportunities for exposure graded exposure has been so incredibly useful in so many other areas of my practice.” -ppt 3

(1.4) *Personal connections*

There was a sense throughout the focus group that each individual EP was involved in researching or working with SM due to differing personal connections with the condition.

“I mean, my my experience, in a sense goes back to my SENCo days when I worked in a high school when when we had a girl who who just didn't communicate and but attended very regularly” – ppt 1

“um so the term selective mutism for me is um. I did my thesis on it as well”- ppt 2

“My eldest son is now 20. He has um autism and he has selective mutism and whilst I recognized the autism when he was very little, probably about 2 1/2 didn't recognize the selective mutism 'cause he's the low profile type”- ppt 3

Therefore, it may be that EPs who are more likely to come into contact and/or work with the condition are those who have some sort of personal connection with it.

(1.5) *Niche speciality*

It would seem as though SM in itself is quite a niche area of working for EPs.

“So I think I've got more experience of selective mutism than many of my colleagues who've been qualified for the same amount of time.”- ppt 2

“Uhm. If my son hadn't been, hadn't had selective mutism, I think I would have continued practicing in bliss, blissful ignorance, thinking that it was something very rare, uh and not something that us ed psychs needed to worry about very much.” -Ppt 3

From the above quotes it would seem that the condition of SM may not be widely known about throughout the EP world, and that it is only through personal preferences that individuals may become involved in working with the condition.

(1.6) Accountability

It appears the focus group felt that although EPs should be working with the condition, in hindsight not enough are. There was also a feeling that due to this there was not enough accountability placed on EPs to work with this condition, and that in reality EPs should be the professionals to do this work:

“It's not going to be. Doing the intervention, but it's going to be. Closely supervising the intervention. Um. So. I'm quite pleased with that. I'm quite I think that well, I mean, I I'm, I'm upset that it's not educational psychology (nods from the group) because I still think that naturally it fits better with educational psychology because we're looking at an anxiety based problem.” - ppt 3

“I suppose also I mean in context, my local authority has got quite a high level of support from other services as well. So it is potentially that they're going towards mental health. Uhm, professionals, maybe historically.”- ppt 2

“my experience of families experiences via the SMIRA Facebook page, which I. I'm on a quite a lot, obviously as a (role in the charity removed) of SMIRA. Uhm is that Educational psychology almost kind of gets let off the hook... when I see this story again and again and again on the SMIRA Facebook page and I'm thinking where are the educational psychologists? We aren't, we aren't, (Ppt 1. Yeah) we aren't, um you know, commissioned for a particular condition in the way that speech therapy is. We work in education. We work on the ground (nodding from Ppt 1). Why? Why isn't it our bread and butter to be working with these kids? It's a psychological based condition. It's not a speech and language based condition. Um and I, you know, I can't. I, as I say, I can't understand.” – ppt 3

There was a sense that although the condition is an anxiety-based condition, which pairs nicely with the role of the educational psychologist (Driver, 2017). Not only are EPs not typically the first port of call for the condition but unlike other services EPs are also not being required to justify their actions.

(1.7) The limitations

A few limitations were mentioned during the focus group in relation to how EPs work with the condition, the pressures placed on them and limitations for the

profession as a whole. The limitations mentioned were time pressure (for both EPs and School):

“it tends to be in a more consultation sort of role um and I think that's probably quite typical for educational psychologists generally, just because of the model of our working and how limited we are with with time and the pressure that we are under to see as many people as we can” – ppt 2

“At the moment for example I've got I I, a young man, who's really struggling and school are really looking at me to sort of be able to provide a solution but with. Very little time. It's really difficult for me to be able to provide the kind of direct work that they would love, but also don't want to use their time.” – ppt2

Lack of direct work:

“I'm never involved, never have been involved with with direct work”—ppt 1

Placing ownership of the 'problem' elsewhere:

“it's often me sort of working with a SENCo or or a teaching assistant or one to one support adult to kind of create a a an environment which is is more comfortable for that young person.” -- Ppt 2

Strategies that have been suggested potentially not being used:

“we just hand over the information to schools, to families and then don't have the opportunity to really follow through and actually discover whether, you know, any any of it is being applied and what the outcomes are, which is hugely frustrating.”—ppt 1

EP's access to knowledge on the condition:

“And I was so aghast at the fact that I'd been trained as an educational psychologist. Um But you know, I don't even remember if selective mutism was mentioned on the course.”—ppt 3

The condition being deemed as not a priority, therefore having to categorise training as something potentially more 'appealing':

"I find it useful to tackle it as anxiety with selective mutism, as a subheading (Ppt 2. Mmm) 'cause I think people can often see the points in training EP's on anxiety." –ppt 3

Powerlessness and frustrations, seemed to arise due to the misunderstandings of the condition and due to previous limitations mentioned such as time constraints:

"you know, like so many things, the assumptions that people can sort it out for themselves by looking something up online or reading a book. Uh. Uh, yes, it's a worry to me."—ppt 1

Unhappy parents:

"I guess the frequency for me in terms of cases that actually come my way, are no no more than perhaps one or two a year. Um I know there are others and we've got one at the moment where we've got some unhappy parents in the background in a statutory case"- ppt 1

And frequency as it would seem as though there are still a high number of individuals with the condition who are being missed:

"2017 that we launched that pathway. And at that time, there were only three children in the whole of (Local Authority) who were getting help for selective mutism. Which is shocking. Um and uh I think now we're up. We're still, we're still miss a lot of them. Um I think we're up to about sort of 50 odd children who are getting help for selective mutism now"- ppt 3

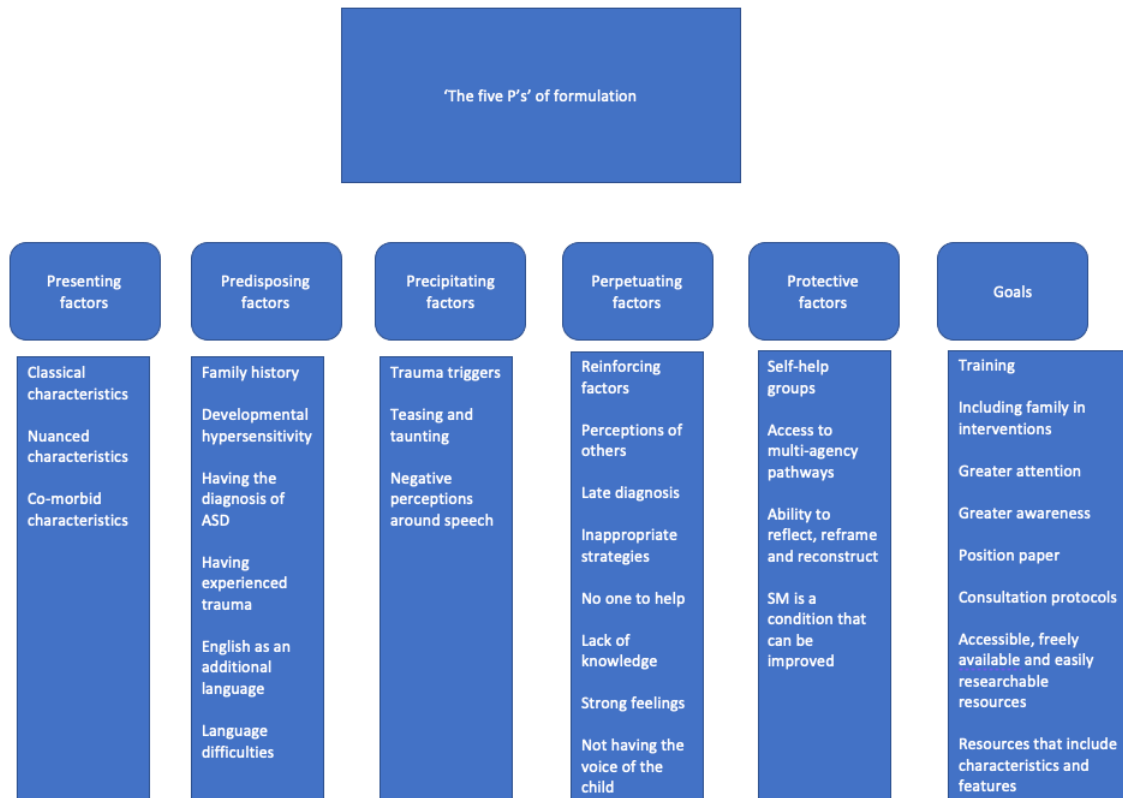


Fig 7. Visual of the theme 'The five Ps' of formulation

(2) 'The five Ps' of formulation (the British Psychological society, 2019)

A technique EPs use to make sense of and try to understand difficulties is that of formulation, particularly 'the five Ps' formulation approach (Patient information Centre, 2018; Peters, 2020; the British Psychological society, 2019). Therefore, in order to explore the condition of SM from the perspective of EPs' it seemed as though the theme of formulation, was the story of the themes that made sense to the researcher. The views of EPs of the condition of SM appeared to follow 'the five Ps' presenting factors, predisposing factors, precipitating factors, perpetuating factors, protective factors, and goals.

(2.1) Presenting factors

The presenting factors are a statement of the presenting problems in terms of emotions, thoughts and behaviours (Honey & Hamilton-Roberts, 2020). In this case the presenting factors appeared to be the characteristics of the condition. There were three types of characteristics mentioned, the classical characteristics, the nuanced characteristics and the co-morbid characteristics.

Classical characteristics that were mentioned were:

“selective mutism is a child who is um too anxious to speak in a social situation where speech might normally be expected, usually at school, um but also speech are quite fluent speech in in other sort of more comfortable circumstances.” –ppt 2

“it's a child who primarily finds the social aspects of verbal communication extremely anxiety provoking.” –ppt 1

“it's a a failure to initiate um. Communication in many cases.”—ppt 3

Nuanced characteristics that were mentioned were (i. children who do not speak within the home, ii. the fact that SM is a communication issue and has two varieties, iii. that individuals with the condition can speak within various settings such as school, iv. that individuals with the condition can present as “outgoing”, v. that the condition may be present due to the individual not liking their voice, vi. that SM is a product of lack of control, and vii. the mention of communication load as a characteristic):

- i. “Uh but of course, over the years I've become aware of, you know, all the nuances. Attached to that, and uh yeah, even children who don't speak at home either.” –ppt 1
- ii. “the more I learn about selective mutism, the more I think that it's really about a communication issue rather than a speech issue or as well as a speech issue... it comes in two varieties, high profile variety where children are unable to speak at all in one setting and the low profile, which is where children are unable to initiate but can respond a little bit.” –ppt 3
- iii. “he's selectively mute but only in really only in really particular situations, um so he could speak in school. He spoke to his friends in school happily. Um. And would answer the teacher if he was absolutely certain that the answer was correct. But any kind of uncertainty um any kind of ambiguity he would clam up”—ppt 3
- iv. “Some you expect to see that withdrawn shy type profile, but there are other young people for whom this is such a successful avoidance strategy that actually they don't present as being particularly um withdrawn. They can be quite outgoing with their friends and their scenes. They're going to other situations or they know they don't want to speak. They will just be quiet and and wait until the for the the situation is over. So I think that withdrawn profile can can look different in different pupils and probably by age as well.” –ppt 2
- v. “The other one that we've come across is is children who quite simply don't like the sound of their voices” –ppt 1
- vi. “It becomes an enormous um fear um and and and again something that they can't control. But they can control their the not talking, bit just not putting themselves in a position where they fear they may be humiliated again.”—ppt 1
- vii. “they don't understand about communication load, which is where certain types of communication are easier than other types of communication. Um 'cause that bamboozles people as to why a child can read aloud but can't answer a question about what they had for tea. Even though the reading aloud is harder words and you know, but the communication load is different in those things.”—ppt 3

And co-morbid characteristics (i. ASD, phobia and social anxiety, ii. Oppositionality, and iii. PDA):

- i. “like a Venn diagram, there's a big chunk of children in the middle of a Venn diagram who have both autism and selective mutism. Um and I think the high profile children. It's more often it's it's more likely to be phobic. Uhm. Whereas the low profile children, it's more like to be social anxiety um.”—ppt 3
- ii. I do believe that I've got something. It's on young people who are so he can be slightly oppositional as well. It is. It is like a a sense of this is what I can control. So I'm going to use this um small element of my life where I can expect or seize this controls. So that's another characteristic of some young people.” —ppt 2
- iii. “in uh identifying it is PDA that's the other bit that's all rather interesting.”—ppt 1

(2.2) Predisposing factors

The predisposing factors are distal external and internal factors that increased the person's vulnerability to SM (Honey & Hamilton-Roberts, 2020). Six potential predisposing difficulties were mentioned throughout the focus group, these included family history (of the condition or of anxiety and depression):

“So as I say, there's often a family history of anxiety or depression or selective mutism as well”—ppt 3

“the family history factor and it's usually mum but but but it's also been dad in one case where I think definitely we were looking at probably um autism spectrum stuff. Uh But you mostly interestingly enough I think it's been the mums who said oh I was like this when I was at school.” —ppt 1

Developmental hypersensitivity:

“it's because these are children who are developmentally hypersensitive, you know”—ppt 3

Having the diagnosis of ASD:

“I think there's a big cohort that are autistic because I think that predisposes to social anxiety, which can then make the trigger. More likely. Um. Yeah, I can't think of anything else I need to say.”—ppt 3

Having experienced trauma:

“Trauma is another one that we've sort of mentioned, but that can be a key factor in the the characteristics.”—ppt 2

English as an Additional Language:

“and English as an additional language is often the another kind of key factor”
—ppt 2

And language difficulties:

“But the reasons behind that anxiety can be so varied, um so many children sort of there might be a language difficulty or social communication difficulty that's sort of sitting behind that social anxiety.” – ppt 2

However, there was also a remark that a child with a diagnosis of SM is no more likely to have ‘faulty’ family relationships than any other child, therefore, this predisposing factor should be taken with a pinch of salt.

“traumatic mutism mutism that follows they you know a major trauma It's a different conditional (ppt 1. Hmm) selective mutism. It tends to be very sudden in onset, and it tends to be pervasive as in in all in all situations, um and they would argue that children who have selective mutism are no more likely to have. A dodgy family.” –ppt 3

(2.3) Precipitating factors

The precipitating factors are the proximal external and internal factors that could potentially trigger SM (Honey & Hamilton-Roberts, 2020). The factors mentioned during the focus group were 'trauma triggers':

"Maggie Johnson would say that there is always a trauma trigger, but it might not be a trauma trigger that you would recognize as a proper trauma in inverted commas. Although it has been for the for the child, and it's usually when they're very, very little, you know, before the age of about, you know, between 2 and 3 ish."—ppt 3

Teasing and taunting:

"there's been one or two occasions where somebody has. Teased or taunted them for the way they've said something and they can't let go. At those moments, you know that's it's been such a an upsetting it is. And I think we we underestimate this for children, that things seem that seem like sort of little things to to adults that perhaps resilient children simply eventually let go of. are not let go of in children who are highly sensitive."—ppt 1

And negative perceptions around speech:

"there'll have been some event where somebody said. Something negative about the speech, and they've reacted by avoiding speaking, and then that's accidentally got reinforced and and become a pattern."—ppt 3

(2.4) Perpetuating factors

The perpetuating factors are the factors that are maintaining the condition (Honey & Hamilton-Roberts, 2020). From the discussion there appeared to be a lot of factors that may maintain the condition such as reinforcing factors (i. positive, ii. negative and iii. Friends, staff and family):

- i. “you've got very. Uh, nurturing. Uhm. Mothers, particularly, who accidentally reinforce that behavior by. Being very um. Supportive of the child, That kind of over over supportive. So they step in and they'll speak for the child. They don't want the child to feel uncomfortable. So once they start doing this avoiding they kind of accidentally reinforce that, give them lots of cuddles. Say it'll be OK.”
–ppt 3
- ii. “have a second parent or a grandparent who's involved, who's very. Negative in their reactions, so they will tell the child off. Make the expectations very clear. So you absolutely must say thank you to Granny for the present. It's very rude if you don't. And they kind of piling on the pressure but in a negative way.”—ppt 3
- iii. “Often I will expect that I will see a lot of reinforcing behaviors from staff and other children as well. That kind of classic, so and so doesn't talk. Oh, it's great that they're friends, talk for them. Um that's a really helpful way of of for us to communicate with this child. So sort of really good intentions often but but quite a lot of um reinforcing behaviors, yeah.” –ppt 2

Perceptions of others (i. being a 'quiet' child, ii. the name and iii. being a misunderstood child):

- i. “We still don’t get us enough of them referred because they're quiet... EP's have. A patch of schools some schools they work with and each year they meet with the SENCOs and they discuss the children who are of concern and then they prioritize some children to see. And what we found was that. We weren't even getting to hear about the children with selective mutism because so we they weren't even being discussed because they're not really causing anybody problem apart from themselves. So you know they're not chucking. Chairs across the classroom. In many cases, they're getting on with their work, and I think schools found it really hard to perceive the wider impact impact of not being able to communicate (nods from the group).”—ppt 3
- i. “It is the fact that they're no trouble to anybody. That's the problem, isn't it?”—ppt 1
- ii. “I don't think the name selective mutism is helpful (ppt 1. No) because it makes people think that it's. I understand that it means medically selective as opposed to pervasive. But a lot of parents think that it means that you're selecting to speak, (Ppt 1. Deliberately choosing, yeah) yeah, choosing. um so I don't think the name is particularly helpful. “ – ppt 3
- iii. “Children with selective mutism, especially low profile selective mutism, are probably the most misunderstood. Cohort that I work with in that you know initially they're assumed to be shy roundabout year as I say age 9 ish people realize that they should be able to in inverted commas do a lot more than they suddenly can and they stop being shy and start being rude. Uhm. Labelled as rude, defiant, um insolent. Uhm. Making negative choices not to speak, um.”—ppt 3

There was a sense that having a late diagnosis can not only maintain the problems but exasperate them:

“I’m expecting them if they’re at secondary school, to have other. You know, school avoidance behaviors probably, possibly depression, um I’m expecting it to be quite entrenched.” – ppt 3

“By the time sometimes these cases do come to us, and they they they are in a position where it’s quite extreme, was quite severe um and and all these sort of associated difficulties of being very withdrawn and shut in very emotive.”—ppt 2

Schools utilising inappropriate strategies:

“Principle to understand for me in selective mutism is this idea of communication load and risk. um and then that, you know, translates into difficulties with. um initiation of, you know, people will often think it’s a speaking problem, so they’ll give children communication cards. But communication cards require initiation. So if you can’t initiate, you can’t use a card (nodding from group) because it’s actually a communication problem, not a speaking problem. Uhm. And things like, you know, um he’s allowed to go to the toilet if he wants to. But it’s again it’s initiation problem. So they probably need taking to the toilet. And it’s it’s this sort of failure to understand the kind of wider picture (Ppt 1. Mmm). “ –ppt 3

Having no one to help:

“where my power sort of falls apart is in. um being the only person, it's really rare (nodding from group). To have you know, professionals who understand about selective mutism,”—ppt 3

Peoples' lack of knowledge:

“so some people have heard of selective mutism, but they think it means the child selecting not to speak and then that leads them down (Ppt 1. Yeah yeah). A particular thought pathway other people haven't heard of it at all and they think the child just shy and they'll grow out of it um and and then the ones who have heard of it and know that it's not a choice will often think that it's a speech problem not a communication problem. And so they'll suggest ineffective um strategies based on substituting speech for another communication form (cough) Which you know which often doesn't work. Sometimes it does, but you know often it doesn't. If it's a if it's a communication issue rather than a speech phobia. So yeah, there's just such a lot of. Knowledge and understanding that needs wider. Sharing in my view”—ppt 3

How the condition invokes strong feelings in others:

“Maggie Johnson says is that, you know, the difference between shy children and selectively mute children is. Does the do you feel hostile towards the child and you know, with such shy children you don't and with selectively mute children. Unfortunately, you do because you just get nothing back.”—ppt 3

And the implication of not having the voice of the child:

“but we don't really have a mechanism, perhaps for asking the young people themselves. Was this what, how you wanted it to be? You know, is this as good as it could have been for you? That's not there.”—ppt 1

(2.5) Protective factors

The protective factors are the strengths and resiliencies that help maintain emotional health (Honey & Hamilton-Roberts, 2020). The protective factors which were mentioned were having self-help groups, potentially due to not being able to gain support elsewhere:

“families I've come across are they're setting up Facebook support groups. So there is that element of Self help happening out there... inevitably they turn to for lack of any kind of service.”—ppt 1

Having access to multi-agency pathways:

“we devised a pathway for (Local Authority) where I work for selective mutism Uhm. Between. Speech therapy, clinical psychology, the CAP service which is our Under 5 service, clinical psychology and educational psychology... So we had to kind of invent a pathway whereby schools can use whichever service.” – ppt 3

How, once access to knowledge is gained, teachers are able to reflect, reframe and reconstruct the condition:

“what I am always delighted by is primary school and say primary schools 'cause that's predominantly where I find this the um there are lots of staff who once to have this information you explain what's going on, who can be very open to that once you develop their understanding and they can see it as a more of an anxiety response.”—ppt 2

And how SM is a condition that can be improved:

“the thing I love about selective mutism is it's one of the very few few things in our profession where if you can get in early enough and do a really good job, the problem can go away. And that's so rare.” –ppt 3

(2.6) Goals

The goals are used to think about the next steps to help the condition (Patient Information Centre, 2018). There were a lot of suggestions that the group made for both supporting the condition and enhancing practice for the future, which lead to potential future steps that EPs could take to help support the condition. Therefore, the goals noted were training (i. for schools, ii. for trainee teachers, iii. for trainee EPs, and iv. for early-year hubs):

- i. “um get really good training into schools because the schools need to know about it.”—ppt 3
- ii. “how we share information about selective mutism with training trainee teachers, and before they even enter the profession, 'cause, if they could come into the job with that understanding it would, it would be such a lovely way to sort of welcome those children into your classroom.”—ppt 2
- iii. “it's it would be so good to see it being part of the EP training uh reels of. separated, more so defined bit of the training program”—ppt 2
- iv. “Uhm, I also we have an early years team who are very in schools, as you know, to ease that transition from nursery into school. There's such an opportunity for us to be working with them and getting the messages out to schools early on. Um and looking for those signs and that first year of school and they know, you know what to do if they are seeing some of those early warning signs in, in young people.” —ppt 2

Including family in interventions:

“When you know when you're looking at interventions, family work has got to be part of a kind of triangulated intervention, (group nodding)”—ppt 3

Having greater attention for the condition:

“I think we need to put this on the table as well as the greater attention we're going to be giving to um you know, the, the neurodiversity bits of the system.”—ppt 1

Having awareness of the condition as part of communication champions role or within the role of practitioners:

“Maybe there's a training opportunity as the communication champions... we also have um. group professional groups within our team. Who are, you know they're not EP's, they're not teachers, they are practitioner level um we have our ASD support assistants. But we also have our SCMH assistants... um that we could we could definitely mobilize”—ppt 1

Having a position paper on the condition:

“the DECP is publishing a sort of whole suite of position papers on various things. Currently there's an excellent, you know, a new one I came across, you know, psychologists working with the autism spectrum. And I wonder if there's a place for something on selective mutism in that sense... uh, sort of nationally agreed. This is where we position ourselves and how we work with schools and families might be really useful.”—ppt 1

Having specific consultation protocols:

“uh, sort of some consultation protocols that sort of cover cover all these essential elements just to sort of so that it's not so it is not dismissed as something that's minor, that they'll grow out of, that you know, parents will have to deal with on their own. You know that that would be most helpful I think.”—ppt 1

Having accessible, freely available and easily researchable resources:

“I think there was some some nice materials already out there and I think Maggie Johnson’s um selective mutism manual contains some amazing resources I think the issue often comes it's it's how how EP's can access such resources. Uhm, any any kind of checklist, consultation protocols I feel needs to be we need to be very freely available. And easily searchable online.”—ppt 2

And having resources that include both characteristics of the condition and features of the condition:

“So to me for it to be kind of. Effective, they would need to be a bit of both, a bit of kinds of principles. Behinds as well as just features of if you see what I mean.”—ppt 3

Discussion

The objective of this research was to explore whether the characteristics observed by Johnson (2017), are present within individuals with SM from a parental perspective and to see if Johnson's (2017) checklist of characteristics could be used to benefit EP's hypothesis building. Ideally, this would lead to further exploration and creation of tools which can help not only EPs but also other professionals explore SM, in order to try to minimise delay for intervention and to help support further research into the condition (Bergman et al. 2008). The findings provide insight into parents' perceptions of their child's condition, the role of the EP in working with the condition and what EPs feel may be needed to further support them when working with this condition. Both qualitative and quantitative data was used in this project, relating to parents' perceptions and EPs' experience, this was chosen to increase the quality of results (Goutaudier et al., 2011). Despite each section of this research project being separate, it was interesting that for both the quantitative and the qualitative aspect it would seem that the participants who took part had personal connections with the condition, suggesting that in a sense they may represent a homogenous group.

Are the characteristics observed by Johnson ([2017] a speech and language therapist specialising in SM) present within individuals with SM from the perspectives of parents of children with SM?

Similarly to the diagnostic criteria for SM (APA, 2013) and what was discussed as the "classical definitions" of SM within the focus group (Ppt 2), parents of children with SM answered "always" to what is typically deemed as the classical characteristics of SM ("only able to talk freely to certain people...", "following a pattern of failure to talk which has lasted for at least one month...", "...stop talking to someone in their 'comfort zone' if they know that someone that is not within their 'comfort zone' is in the room..." and "...show a big difference between: Talking and interacting... with people in their 'comfort zone' and avoidance...with people not in their 'comfort zone'"). Furthermore, as mentioned in the focus group and SM literature, initiation is often reported as being a barrier for children with SM (Johnson & Wintgens, 2015) therefore it is encouraging to note that parents selected "never" for "is your child able to initiate conversations with people outside of their 'comfort zone?'". From a research perspective this is very promising not only suggesting that

the children were likely diagnosed correctly, but it also possibly enhances the likelihood that the other characteristics reported by the parents are present within a wider population of individuals with SM.

Within the SM literature (but not within the diagnostic criteria) there is mention of an SM 'freeze' whereby individuals will freeze when spoken to, and mention of the fact that children with SM can often communicate non-verbally with individuals outside of their 'comfort zone' (Diliberto & Kearney, 2016; Johnson & Wintgens, 2015; Schwenck et al., 2021; Sharkey & McNicholas, 2008). This research has been further supported through the findings that the parents within this study answered, "very often" to "does your child 'freeze'... when someone outside of their 'comfort zone' is near" and "does your child prefer to use non-verbal communication (e.g. nodding) and alternative means of communication (e.g. drawing/writing) with, or in front of, people outside of their 'comfort zone'...".

Within the focus group there was a hypothesis that high-profile children with SM were more likely to be phobic, whereas children with low-profile SM were more likely to have social anxiety (Ppt 3). This hypothesis (despite not having been researched) could potentially explain the characteristics that sit within the "sometimes" category "Does your child try and avoid situations where they fear they will be expected to talk...", or "Does your child opt for silence?". Due to the first characteristic being consistent with that of someone who would have a phobia and the second being consistent of someone with social anxiety (Higuera, 2018; Johnson & Wintgens, 2015). Therefore, this idea of characteristics being dependent on type of SM, would be in line with the consensus of "sometimes" as opposed to "always" or "very often". Additionally, during the focus group there was further mention of other possible co-morbid characteristics that can sometimes be present within SM (Oppositionality and PDA), therefore, when assessing characteristics of this condition these should also be taken into consideration.

Contrary to previous literature (APA, 2013; Collins-Donnelly, 2013; Ruiz, 2020) the parents' within this study answered "never" for "does your child complain that they want to talk but their voice just gets stuck in their throat?", "does your child say that when they try and speak they get a rapid heart-rate, shortness of breath and/or a tightness in their chest?" and "Has your child ever started to panic, had a meltdown or avoided further contact after talking?". Parents also answered "never" for "does your child ever deny talking, stop talking and/or reject praise for talking,

because they felt that this would lead to people expecting them to talk more because of it?”. Therefore, it could be that these symptoms may actually not be a characteristic of SM, as previous consensus with the “classical definitions” (ppt 2) could suggest this, or it may be that these characteristics only happen in a small portion of individuals with the condition, and due to the small sample size this may be why they were not seen within this study.

Will awareness of these characteristics be beneficial in helping EPs elicit testable hypotheses?

Knowledge seemed to be a consistent message throughout all the themes, within the EP world having knowledge on SM meant that you were in the minority, as it seemed as though it may be a niche speciality which meant that having more knowledge ensured more cases were brought forward to them. But for others the stark reality of the lack of knowledge within the community on the condition lead to frustrations and potentially the frequency of cases not being where it should be, this in turn could be the reason for the presence of the “unhappy parents” (Ppt 1). Within Cleave’s (2009) research the importance of EPs understanding and having knowledge of the causes of SM, to elicit testable hypotheses is discussed. Therefore, it was encouraging to note that many predisposing factors (family history [of the condition or of anxiety and depression], Developmental hypersensitivity, Having the diagnosis of ASD, Having experienced trauma, EAL, and language difficulties) and precipitating factors (trauma triggers, teasing and taunting, and negative perceptions around speech) were discussed throughout the focus group, which married up with previous research (Black & Uhde, 1995; Cleave, 2009; Oades & Patterson, 2015; Omdal, 2007; Remschmidt et al., 2001; Segal, 2003; Stambaugh & Sood, 2014) However, despite the vast amount of knowledge held by the participants during the focus group, there were still aspects mentioned (with regards to trauma being a key factor in the characteristics) that have not been found in the literature, possibly further highlighting how important it is for more research into the condition and to create methodologically strong and psychometrically sound measures of characteristics of SM (Bergman et al. 2008).

Additional findings from the questionnaire

Interestingly, despite SM being reclassified in the DSM-V as an anxiety disorder, the 'typical' presentation of anxiety did not seem to be overtly present within the sample population of this study (APA, 2013). The majority of parents answered "never" for both "does your child say that when they try and speak they get a rapid heart-rate, shortness of breath and/or a tightness in their chest?" and "has your child ever started to panic, had a meltdown or avoided further contact after talking?", with the majority answering only "sometimes" for "Does your child try and avoid situations where they fear they will be expected to talk? E.g. avoiding going to a family members house who always asks them questions or expects them to say please and thank you by asking to stay at home, dawdling or making a mess". Therefore, this finding could support that of Driessen et al (2020) who suggest that SM is in fact not originated from anxiety, but that it may be a co-morbidity of SM, due to the finding that 80% of children with a diagnosis of SM who took part in their study had a co-morbid diagnosis of anxiety disorder, yet it was unclear how the anxiety manifested in the remaining 20% of their participants who lack this additional diagnosis.

Furthermore, contrary to previous literature that "language minority" individuals are at a higher risk of SM than the general population only 17.4% of the population within this sample were multi-lingual (Toppelberg et al., 2005, p.592). Therefore, it is not possible to know from this data whether there are different presentations of characteristics within this population of individuals, as has been previously suggested (Mayworm, et al., 2015; Toppelberg et al., 2005).

Additional findings from the focus group

The overall sense of the focus group was that not enough work is being completed with these young people, especially with regards to direct work. It seemed as though SM may not be a priority to some within the EP profession and within the school environment, therefore there was a lack of time for work to be undertaken and energy with regards to strategies suggested not being utilised. A common issue that is frequently mentioned within SM self-help social media pages and within research on SM, is that SM is not within the remit of any one professional (Keen et al, 2008), similarly this was mentioned in the focus group, but with the caveat that in fact EPs should be held accountable. There was a sense that SM should be within the remit

of EPs, more so than other professionals due to the nature of the condition, and the nature of the EPs role. Furthermore, due to the systemic nature of the perpetuating factors mentioned (reinforcing factors, perceptions of others, late diagnosis, having no one to help, peoples' lack of knowledge, how the condition invokes strong feelings in others, and the implication of not having the voice of the child), EPs are well-placed to help with these concerns due to the consultative nature of their role and their unique systemic approach of working within the whole system of the child, future goals discussed during the focus group also highlighted the need for including families within the interventions (Ashton & Roberts, 2006; Boyle and Lauchlan, 2009). Additionally, it was mentioned that unlike other conditions that EPs work with on a daily basis, SM is a condition where "if you can get in early enough... the problem can go away" (Ppt 3), therefore due to the age ranges EPs work with (0-25 years old), they may be in the prime position to work with those early years settings in order to help support knowledge and help provide early identification and early intervention (Welsh Government, 2016).

Despite the somewhat bleak picture that may have been painted within the focus group there were moments where EPs were able to share their best practice techniques learnt through working with the condition and share what their local authority had been able to put in place such as multi-agency pathways. There was mention of the success stories being shared within the self-help groups, so that parents were able to see that although it may be tough now that it can get better. But perhaps most importantly due to the literature suggesting that teachers may harbour negative feelings about children with SM, possibly construing them as defiant, it was encouraging that participants spoke about how being given access to knowledge on the condition enabled teachers to reflect, reframe and reconstruct the condition, suggesting that even small changes within the system can have a substantial impact (Cleave, 2009; Cline & Baldwin, 1998; Fox, 2009; Gameson et al., 2003). EPs discussed how important drawing greater attention to the condition and training, for schools, trainee teachers, trainee EPs, communication champions and early-year hubs would be for future practice.

Participants within the focus group also discussed what would not only help their practice, but the practice of others in the role. Firstly, a position paper on the condition was mentioned which could help fellow EPs understand how to work with schools and families on the condition. Secondly, specific consultation protocols that

cover the “essential elements” of SM (ppt 1) as well as having accessible, freely available and easily researchable resources on SM were deemed as possibly helpful in making sure that SM is a condition that EPs are actively ‘ruling out’ when hypothesis building. Finally, in terms of having a specific checklist on SM characteristics there was mention that although a checklist may be helpful on the specific characteristics, it may be more effective to have a checklist that contains both the characteristics and the features of SM.

Links to psychological theory

Two psychological theories which seem pertinent to the findings of this research are social representation theory (Moscovici & Herzlich, 1973) and attribution theory (Fiske & Taylor, 1991). Social representation theory is the “theory of social knowledge” which is specifically concerned with how “individuals, groups and communities collectively make sense of socially relevant or problematic issues, ideas and practices” (Marková, 2008, p. 483; Moloney et al., 2014, p. 2). Whereas attribution theory focuses on how “the social” perceiver uses information to arrive at causal explanations for events. It examines what information is gathered and how it is combined to form a causal judgment” (Fiske & Taylor, 1991, p. 23, Mcleod, 2012). Both shall be discussed in relation to the findings of the research.

Social representation theory suggests that knowledge is always actively constructed by social agents, it is never disinterested (Howarth, 2006). These social agents speak from different positions and have different “social stakes” in either maintaining or challenging “the hegemonic social representations that invade their realities” (Howarth, 2006, p.77). There are differing points of access to the construction of social reality within different social groups in the public sphere, which leads to different levels of social inclusion and exclusion (Howarth, 2006). All of this has an impact on the reification and legitimisation of knowledge systems (Howarth, 2006). This could potentially explain why there was a large consensus with regard to the “classical characteristics” (ppt 2) for the questionnaire yet, less of a consensus for potentially lesser-known characteristics such as “does your child complain that they want to talk but their voice just gets stuck in their throat?” and the ‘typical’ presentations of anxiety (Collins-Donnelly, 2013). As there are discussions around the “classical definitions” (ppt 2) on the Facebook self-help pages that the participants were recruited from, with sharing of information sheets on the condition

and personal stories shared naming these traits, it is likely that the participants knowledge has been actively shaped through their experiences within these groups. Furthermore, if individuals such as teachers have not heard of the condition or have 'made sense' of the condition through social groups that are not knowledgeable on SM, then it could explain the research surrounding teachers' perceiving children with SM as defiant (Cleave, 2009). Therefore, in order for these views and representations to be shaped there needs to be discussions around the topic, however, this may be where SM is particularly let down due to the silent nature of the condition.

In terms of attribution theory Juvonen (1991) found that if a child perceives a peer as being 'different' they are more likely to subsequently 'reject' them. This may in part explain the findings of the condition invoking strong feelings in others, particularly teaching staff. As it could be due to their probable lack of knowledge on the condition, therefore likely assuming the child is being defiant, especially as mentioned by ppt 3 they are likely to "get nothing back" from these individuals (Cleave, 2009). However, as stated during the focus group, being given access to knowledge on the condition appeared to enable teachers to reflect, reframe and reconstruct the condition, suggesting that even small changes within the system can have a substantial impact. This is somewhat supported through the research of Marom et al. (2007) who found that through giving precise information surrounding the disabilities of their peers to typically developing (TD) classmates, the TD children had improved attitudes towards their peers with SEN. Highlighting the importance of information sharing and training on the condition, not just for the child's acceptance but also to improve the mental wellbeing of teachers.

These theories both emphasise the potential impact that information sharing can have on knowledge development of SM and highlight the importance of effective information sharing. However, as mentioned above due to the silent nature of the condition it is likely that awareness raising may need to come from external agencies, but this may not be easy. Within social representation theory it is recognised that "in the process of formation of a representation there is always both conflict and cooperation", therefore there is always scope for "re-interpretation, re-evaluation and debate", which allows for meanings to be "contested, negated and transformed" (Howarth, 2006, p.77; Marková, 1998, p.377). However, the development of this transformation requires a community of others, as meanings can

only be relational, meaning the dispute of meanings can only occur in relationship (Howarth, 2006). Therefore, to enable change through knowledge development a community of professionals would be required.

Utilising the work of Bronfenbrenner

The concept of Bronfenbrenner's model is a means of understanding the individual development of a child through considering the influence that complex systems of relationships and multiple levels of surrounding environments may have (Guy-Evans, 2020; Kovac, 2018). As SM is both a personal condition yet can also have an influence on the wider systems around the child or young person, this theory seemed pertinent to the findings, this is showed through the use of the double headed arrows on the diagram below.

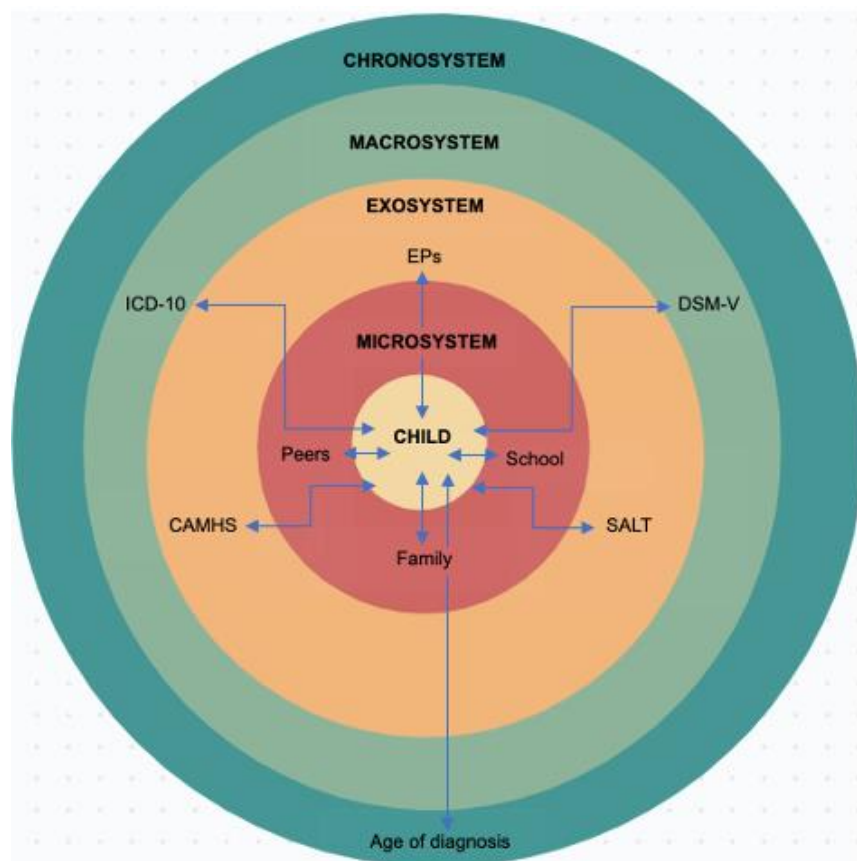


Fig. 8 Bronfenbrenner's Ecological systems theory model

As discussed above SM may impact individuals negatively in differing ways, specifically for the child with a diagnosis of SM, SM has been related to difficulties with overall psychological functioning (Mayworm et al., 2015). However, the other difficulties such as:

- Rejection or difficulties with peers;
- School failure;
- Teacher's potentially harbouring negative feelings about the child with SM, possibly construing them as defiant;
- Aggravated intrafamilial relationships; and
- Reduced opportunities for social interaction which could not only restrict involvement in everyday activities with other children; dissuade individuals from attending school or completing academic work; but it could also potentially lead to a developmental delay of appropriate language skills (Cleave, 2009; Diliberto & Kearney, 2016; Henkin, & Bar-Haim, 2015; Mayworm et al., 2015; Muchnik et al., 2013; Krysanski et al., 2003).

Both have a direct impact and are a direct impact within the Microsystem, the area that contains the individuals that the child has direct contact with (Ryan, 2001). Within the Exosystem, the large social system with which the child does not function directly, the remit debate lies, along with the implications misdiagnosis may have (Caroll, 2021; Ryan, 2001; Schwartz & Shipon-Blum, 2005; Spiro, 2021). The implications that both the remit debate and misdiagnoses have for the family and the individual are surrounding not only possible delay in diagnosis but potential treatment delays and individuals such as family members turning to self-help groups "for lack of any kind of service" (Lawler, n.d.; ppt 1). Within the Macrosystem, the area which comprises of laws, cultural values and customs, the main diagnostic manuals (DSM-V and ICD-10) lie as they are what currently constitute the diagnosis of SM (Ryan, 2001). Currently both the DSM-V and ICD-10 not only use differing names for the condition (SM and elective mutism) but there are also differing guidelines for both, which could potentially lead to confusion for not only the professionals who adhere to them but the family and individuals themselves (APA, 2013; WHO, 1992). Finally, within the Chronosystem, the area that encompasses "the dimension of time as it relates to the child's environments", age of diagnosis lies (Ryan, 2001, p. 3). As stated above the cardinal symptom of SM can be treated if diagnosed early and given appropriate management, however if treatment is delayed after the age of seven this is less likely to be the case, therefore the age of the

diagnosis could have an impact on the individual with the condition (Schwartz & Shipon-Blum, 2005).

Conversely, this diagram also provides a means of visualising the support surrounding the child. As stated above EPs may be best placed to work with early years settings in order to help support knowledge and help provide early identification and early intervention (Welsh Government, 2016). Teachers are in a prime position to help promote emotional and social skills development within pupils, along with being “mothering, caring, nurturing and protecting” (Dean, 2012, p.116; Geddes, 2006). Finally, parents accessing self-help groups shows a desire to help their child through any means necessary.

Bronfenbrenner’s model helps to show that not only is SM a complex disorder in and of itself but also how the wider systems around the child can also be impacted, as well as how the individual can be impacted by the wider system.

Future research

Despite there being some overlap in the ‘presenting issues’ mentioned in the focus group, it was apparent that some characteristics mentioned by the EPs were not present within Johnson’s (2017) characteristic checklist. For example, individuals with the condition can speak within various settings (such as school); and that the condition may be present due to the individual not liking their voice. It may be that different professionals are able to notice differing behaviour traits, therefore, future research could explore adding the characteristics mentioned via the focus group to the questionnaire and disseminating to a wider audience. Furthermore, due to the high volumes of research into the misdiagnosis of SM as ASD, exploring these characteristics within this population would be highly desirable. Finally, although mentioned in the focus group the remit debate has not been researched, therefore research with the professionals who are involved (EPs, Speech and Language Therapists and Child and Adolescent Mental Health Service workers) could help to understand who may be best placed to work with this condition.

Limitations

There was relatively low completion rate for the questionnaires, limiting the generalisation of the results. Upon reflection the choice of recruitment groups may have inadvertently affected this as mentioned in the focus group, as these self-help

groups on Facebook also attract parents who are unable to find support elsewhere, therefore are unlikely to have a diagnosis, this could explain the high rate of volunteers who were ineligible for the study as they did not meet the inclusion criteria. Furthermore, the qualitative aspect of this project was completed with three EPs who all had personal interest and personal connections with the condition, possibly suggesting a high chance that the sample is biased, yet this is a concept that reflexive TA is less interested in.

Strengths

For context, this research was undertaken during a period of significant disruption arising from lockdowns and social distancing measures introduced in response to the Covid-19 pandemic between 2020-2022. During this time the 'new ways of working' were being developed especially consultations, conferences, and interviews via online platforms. Therefore, considering these unprecedented circumstances the researcher did well to recruit a substantial number of participants and complete this research. Further strengths to this piece of research, included the research's ability to shed light on an area that has been under-researched, the researcher's ability to maintain parental voice, as well as gaining the views of EPs on the condition.

Conclusion

As reported in the questionnaires, parents typically answered the questionnaire in line with both the literature and the discussions within the focus group, suggesting that there is a high chance that most of the characteristics observed by Johnson (2017) are present within individuals with SM. During the focus group there was mention that a checklist of characteristics may be beneficial for aiding EP's hypothesis building, especially if it includes features of the condition, but that a checklist alone may not be enough, suggesting that there is a need for more training, position papers on working with the condition, consultation protocols, and accessible, freely available, and easily researchable resources.

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Appendices

Appendix A- Qualtrics questionnaire for part 1 Children with Selective Mutism's presentations of behaviour

Children with Selective Mutism's presentations of behaviour

Start of Block: Default Question Block

Q1 Participant information sheet

I am a trainee Educational Psychologist who would like to conduct a research study exploring the characteristics of Selective Mutism (SM) and their applicability for the role of the Educational Psychologist (EP). You are being invited to take part in this research study. Before you decide whether you would like to participate it is important for you to understand why the research is being conducted and what it will involve. Please take your time and read the following information carefully and please ask if there is anything you are unclear about or need more information on. Your time is greatly appreciated.

What is the purpose of the project?

The purpose of this research is to explore your perceptions of the characteristics of Selective Mutism (SM). The findings will be used to form part of my Thesis which I will submit as a requirement of my Doctorate in Educational Psychology.

Do you have to take part?

Participation in this research is completely voluntary. Should you decide to take part you will be asked to complete a consent form declaring that you have read and understood the information in this document and that you consent to participate in the research. Should you change your mind about participating, you can withdraw from the study as long as it is before you have submitted the questionnaire. After such a time where you have submitted the questionnaire the data will not be traceable to you and so it will not be possible to recover it, and it will no longer be possible to remove it. **What will happen if you take part?** If you wish to take part in this study you will be asked to complete a questionnaire. The questionnaire will be about your understanding of what characteristics are present within SM. Data collected will be from the completed questionnaires. Questionnaires will be anonymous. Only anonymised data will be presented in the report so that no individual is identifiable in this way either. **What are the possible disadvantages and risks of taking part?** There are no known disadvantages envisaged in taking part in this study; however, if you at any point find the questionnaire to be distressing please indicate to the researcher if this is the case or stop taking part. If you have any queries about the research, please contact the researcher or Dr Gemma Ellis, research supervisor. **What are the possible benefits of taking part?** This study will not provide any specific benefits to individuals; however, it may provide insight into potential characteristics of SM which may impact how Educational Psychologists and other practitioners who may work with the condition in the future. **What will happen to the results of the research study?** The results of the study will be written up and submitted for assessment contributing towards the researcher's doctorate in Educational Psychology. The

results may be published and used in presentations but in an anonymous way. **Who has reviewed the project?** This research is conducted within the requirements of the School of Psychology Research Ethics Committee at Cardiff University and in accordance with both the British Psychological Society's Ethical Code of conduct (BPS, 2009) and the Health and Care Professions Council (HCPC, 2016). This project is being overseen by my supervisor Dr Gemma Ellis. **Thank you for taking the time to read this information.**

Yours faithfully,
Kathryn Edwards

If you have any questions, please contact us or our project supervisor

Contact details of researcher: Kathryn Edwards, School of Psychology, Cardiff University, Tower Building, 30 Park Place, Cardiff, CF10 3EU; email: Edwardskb@cardiff.ac.uk

Contact details of Research Supervisor: Dr Gemma Ellis, Professional Tutor, Doctorate in Educational Psychology, School of Psychology, Cardiff University, Tower Building, 30 Park Place, Cardiff, CF10 3EU; email: ellisg6@cardiff.ac.uk

Contact details of Cardiff University's Research Ethics Committee: School of Psychology, Cardiff University, Tower Building, 30 Park Place, Cardiff, CF10 3EU; email: psychethics@cardiff.ac.uk

Q2 Consent Form Name of student conducting this research: Kathryn Edwards

- 1 *I confirm that I have read and understand the information sheet for this project.*
- 2 *I understand that my responses will be used as part of the research project described in the information sheet.*
- 3 *I understand that my participation in this study is voluntary and that I can withdraw before submitting my responses.*
- 4 *I understand that it is not possible to withdraw my answers once they have been submitted.*
- 5 *I understand that I am free to ask any questions at any time (via the contact details shown below)*
- 6 *I understand that examples of my experiences will be noted and analysed but only presented in an anonymous state.*
- 7 *I understand that the researcher must work in accordance to the Ethical Code of Conduct set by the School of Psychology Research Ethics Committee at Cardiff University and The British Psychological Society (2009).*
- 8 *I agree to take part in the above research project.*

Contact details of researcher: Kathryn Edwards, School of Psychology, Cardiff University, Tower Building, 30 Park Place, Cardiff, CF10 3EU; email: Edwardskb@cardiff.ac.uk
Contact details of Research Supervisor: Dr Gemma Ellis, Professional Tutor, Doctorate in Educational Psychology, School of Psychology, Cardiff University, Tower Building, 30 Park Place, Cardiff, CF10 3EU; email: ellisg6@cardiff.ac.uk
Contact details of Cardiff University's Research Ethics Committee: School of Psychology, Cardiff University, Tower Building, 30 Park Place, Cardiff, CF10 3EU; email: psychethics@cardiff.ac.uk The

information provided will be held in compliance with GDPR regulations. Cardiff University is the data controller and James Merrifield is the data protection officer (inforequest@cardiff.ac.uk). The lawful basis for processing this information is public interest. This information is being collected by [Kathryn Edwards]. The information on the consent form will be held securely and separately from the research information. Only the researcher will have access to this form and it will be destroyed after 7 years. The research information you provide will be used for the purposes of research only and will be stored securely. Only the researcher will have access to this information. After 2 weeks the data will be anonymised (any identifying elements removed) and this anonymous information may be kept indefinitely or published unusual with the data (sharing it with people outside the EU or using it for teaching) then you will need to edit this notice].

	Yes (1)	No (2)
I confirm that I have read and understand the information sheet for this project and I agree to take part in the above research project. (1)	<input type="radio"/>	<input type="radio"/>

Skip To: Q3 If Consent Form Name of student conducting this research: Kathryn Edwards I I conf... = I confirm that I have read and understand the information sheet for this project and I agree to take part in the above research project. [Yes]

Skip To: End of Survey If Consent Form Name of student conducting this research: Kathryn Edwards I I conf... = I confirm that I have read and understand the information sheet for this project and I agree to take part in the above research project. [No]

Q3 Has your child got a professional diagnosis of Selective Mutism?

- Yes (1)
- No (2)

Skip To: Q4 If Has your child got a professional diagnosis of Selective Mutism? = Yes

Skip To: End of Survey If Has your child got a professional diagnosis of Selective Mutism? = No

Q4 What is your nationality?

Q5 What is your child's gender?

- Male (1)
 - Female (2)
 - Non-binary / third gender (3)
 - Prefer not to say (4)
-

Q5 Does your child speak more than one language e.g. bi-lingual or trilingual?

- Yes (1)
 - No (2)
-

Q11 These questions are around how your child behaves in different settings, think about how your child compares to their peers. The questions will be asked in the present tense however if your child has now overcome their Selective Mutism please answer these questions as though they are past tense. E.g. your child was only able to talk freely to certain people.

	Always (1)	Very often (2)	Sometimes (3)	Rarely (4)	Never (5)	Not Relevant (6)
Is your child only able to talk freely to certain people? e.g. you and others that they feel comfortable with or in other words people who would be in their 'comfort zone'. (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q12 These questions are around how your child behaves in different settings, think about how your child compares to their peers. The questions will be asked in the present tense however if your child has now overcome their Selective Mutism please answer these questions as though they are past tense. E.g. your child was only able to talk freely to certain people.

	Always (1)	Very often (2)	Sometimes (3)	Rarely (4)	Never (5)	Not Relevant (6)
Does your child follow a noticeable pattern of 'failure to talk' which has lasted for at least one month (or two months if it's within a new setting e.g. just moved schools). (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q13 These questions are around how your child behaves in different settings, think about how your child compares to their peers. The questions will be asked in the present tense however if your child has now overcome their Selective Mutism please answer these

questions as though they are past tense. E.g. your child was only able to talk freely to certain people.

	Always (1)	Very often (2)	Sometimes (3)	Rarely (4)	Never (5)	Not Relevant (6)
Does your child stop talking to someone in their 'comfort zone' if they know that someone that is not within their 'comfort zone' is in the room and/or is able to hear them? E.g. your child may speak to you in an empty waiting room but will stop when someone comes into the room or your child may talk to their friend in the house but not at school where other children could hear them speak. (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q14 These questions are around how your child behaves in different settings, think about how your child compares to their peers. The questions will be asked in the present tense however if your child has now overcome their Selective Mutism please answer these

questions as though they are past tense. E.g. your child was only able to talk freely to certain people.

	Always (1)	Very often (2)	Sometimes (3)	Rarely (4)	Never (5)	Not Relevant (6)
Does your child show a big difference between: Talking and interacting (smiling/laughing) freely with people in their 'comfort zone' and avoidance, non-verbal communication (e.g. nodding), silence or strained not typical communication (e.g. one word answers that may not fit with the context) with people not in their 'comfort zone' (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q15 These questions are around how your child behaves in different settings, think about how your child compares to their peers. The questions will be asked in the present tense however if your child has now overcome their Selective Mutism please answer these

questions as though they are past tense. E.g. your child was only able to talk freely to certain people.

	Always (1)	Very often (2)	Sometimes (3)	Rarely (4)	Never (5)	Not Relevant (6)
Does your child 'freeze' (their body gets rigid and they have a fixed facial expression that can sometimes be mistaken for a smirk) when someone outside of their 'comfort zone' is near, even though they were relaxed just before the person entered? (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q16 These questions are around how your child behaves in different settings, think about how your child compares to their peers. The questions will be asked in the present tense however if your child has now overcome their Selective Mutism please answer these

questions as though they are past tense. E.g. your child was only able to talk freely to certain people.

	Always (1)	very often (2)	Sometimes (3)	Rarely (4)	Never (5)	Not Relevant (6)
Does your child complain that they want to talk but their voice just gets stuck in their throat? (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q17 These questions are around how your child behaves in different settings, think about how your child compares to their peers. The questions will be asked in the present tense however if your child has now overcome their Selective Mutism please answer these questions as though they are past tense. E.g. your child was only able to talk freely to certain people.

	Always (1)	Very often (2)	Sometimes (3)	Rarely (4)	Never (5)	Not Relevant (6)
Does your child say that when they try and speak they get a rapid heart-rate, shortness of breath and/or a tightness in their chest? (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q18 These questions are around how your child behaves in different settings, think about how your child compares to their peers. The questions will be asked in the present tense however if your child has now overcome their Selective Mutism please answer these

questions as though they are past tense. E.g. your child was only able to talk freely to certain people.

	Always (1)	Very often (2)	Sometimes (3)	Rarely (4)	Never (5)	Not Relevant (6)
Does your child prefer to use non-verbal communication (e.g. nodding) and alternative means of communication (e.g. drawing/writing) with, or in front of, people outside of their 'comfort zone', even if that makes them look different from others around them? (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q19 These questions are around how your child behaves in different settings, think about how your child compares to their peers. The questions will be asked in the present tense however if your child has now overcome their Selective Mutism please answer these

questions as though they are past tense. E.g. your child was only able to talk freely to certain people.

	Always (1)	Very often (2)	Sometimes (3)	Rarely (4)	Never (5)	Not Relevant (6)
Does your child ever deny talking, stop talking and/or reject praise for talking, because they felt that this would lead to people expecting them to talk more because of it? (This is not the same as denying talking because you would get into trouble for talking). (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q20 These questions are around how your child behaves in different settings, think about how your child compares to their peers. The questions will be asked in the present tense however if your child has now overcome their Selective Mutism please answer these

questions as though they are past tense. E.g. your child was only able to talk freely to certain people.

	Always (1)	Very often (2)	Sometimes (3)	Rarely (4)	Never (5)	Not Relevant (6)
Does your child try and avoid situations where they fear they will be expected to talk? E.g. avoiding going to a family members house who always asks them questions or expects them to say please and thank you by asking to stay at home, dawdling or making a mess. (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q21 These questions are around how your child behaves in different settings, think about how your child compares to their peers. The questions will be asked in the present tense however if your child has now overcome their Selective Mutism please answer these

questions as though they are past tense. E.g. your child was only able to talk freely to certain people.

	Always (1)	Very often (2)	Sometimes (3)	Rarely (4)	Never (5)	Not Relevant (6)
Does your child opt for silence? E.g. decides in advance that they won't talk, making no attempt to speak to those outside of their 'comfort zone' or by letting you know that they have no intention to talk? (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q22 These questions are around how your child behaves in different settings, think about how your child compares to their peers. The questions will be asked in the present tense however if your child has now overcome their Selective Mutism please answer these questions as though they are past tense. E.g. your child was only able to talk freely to certain people.

	Always (1)	Very often (2)	Sometimes (3)	Rarely (4)	Never (5)	Not Relevant (6)
Is your child able to initiate conversations with people outside of their 'comfort zone'? (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q23 These questions are around how your child behaves in different settings, think about how your child compares to their peers. The questions will be asked in the present tense however if your child has now overcome their Selective Mutism please answer these questions as though they are past tense. E.g. your child was only able to talk freely to certain people.

	Always (1)	Very often (2)	Sometimes (3)	Rarely (4)	Never (5)	Not Relevant (6)
Is your child able to answer questions if the conversation was initiated by someone outside of their 'comfort zone', but, they appear to have a 'frozen' facial expression, or a rigid, quiet, whispered or distorted voice? (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q24 These questions are around how your child behaves in different settings, think about how your child compares to their peers. The questions will be asked in the present tense however if your child has now overcome their Selective Mutism please answer these

questions as though they are past tense. E.g. your child was only able to talk freely to certain people.

	Always (1)	Very often (2)	Sometimes (3)	Rarely (4)	Never (5)	Not Relevant (6)
Has your child ever started to panic, had a meltdown or avoided further contact after talking? (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q26 Was this questionnaire easy to understand?

- Yes (1)
- No (2)
- If you have answered No , please could you help me by providing a little feedback (3) _____

Page Break

Q9 Debrief Information To participants, Thank you for volunteering to participate in this study, your participation is appreciated, and I hope that you enjoyed taking part. The purpose of this study was to explore the characteristics of Selective Mutism and their applicability for the role of the Educational Psychologist. You are reminded that your responses will be kept confidentially in a secure location. No names will be associated with any findings within the report. If you have any questions about the study please do not hesitate to contact the researcher or her supervisor (contact details below). Regards, Kathryn Edwards **If you have any questions, please contact us or our project supervisor**

Contact details of researchers: Kathryn Edwards, School of Psychology, Cardiff University, Tower Building, 30 Park Place, Cardiff, CF10 3EU; email:

Edwardskb@cardiff.ac.uk Contact details of Research Supervisor: Dr Gemma Ellis, Professional Tutor, Doctorate in Educational Psychology, School of Psychology, Cardiff University, Tower Building, 30 Park Place, Cardiff, CF10 3EU; email:

ellisg6@cardiff.ac.uk Contact details of Cardiff University's Research Ethics Committee: School of Psychology, Cardiff University, Tower Building, 30 Park Place, Cardiff, CF10 3EU; email: psychethics@cardiff.ac.uk

The information provided will be held in compliance with GDPR regulations. Cardiff University is the data controller and James Merrifield is the data protection officer (inforequest@cardiff.ac.uk). The lawful basis for processing this information is public interest. This information is being collected by [*Kathryn Edwards*]. The information on the consent form will be held securely and separately from the research information. Only the researcher will have access to this form and it will be destroyed after 7 years. The research information you provide will be used for the purposes of research only and will be stored securely. Only the researcher will have access to this information. After 2 weeks the data will be anonymised (any identifying elements removed) and this anonymous information may be kept indefinitely or published *unusual with the data (sharing it with people outside the EU or using it for teaching) then you will need to edit this notice*].

End of Block: Default Question Block

Appendix B- Focus Group Invite

Dear Educational Psychologist,

I would like to invite you to take part in a focus group (small discussion group) on (insert date, time and location). The purposes of this study are to explore your perceptions of the applicability of a Selective Mutism (SM) checklist in order to aid hypothesis building within the Educational Psychology (EP) profession. The focus group should last between one to two hours.

The focus group will provide an opportunity for you to discuss with others the topic of SM and what it means to the profession.

More background information will be sent to those who choose to participate before the focus group, this shall be sent via e-mail. Your views will be used to help the researcher form part of her Thesis which I will submit as a requirement of my Doctorate in Educational Psychology.

If you would like to take part in the focus group on (insert date) please let the researcher know by emailing. The researchers contact details can be found below.

Yours faithfully,
Kathryn Edwards

If you have any questions, please contact us or our project supervisor

Contact details of researchers:

Kathryn Edwards, School of Psychology, Cardiff University, Tower Building, 30 Park Place, Cardiff, CF10 3EU; email: Edwardskb@cardiff.ac.uk and

Contact details of professional tutor:

Dr Gemma Ellis, Professional Tutor, Doctorate in Educational Psychology, School of Psychology, Cardiff University, Tower Building, 30 Park Place, Cardiff, CF10 3EU; email: ellisg6@cardiff.ac.uk

Contact details of Cardiff University's Research Ethics Committee:

School of Psychology, Cardiff University, Tower Building, 30 Park Place, Cardiff, CF10 3EU; email: psychethics@cardiff.ac.uk

The information provided will be held in compliance with GDPR regulations. Cardiff University is the data controller and James Merrifield is the data protection officer (inforequest@cardiff.ac.uk). The lawful basis for processing this information is public interest. This information is being collected by [*Kathryn Edwards*].

The information on the consent form will be held securely and separately from the research information. Only the researcher will have access to this form and it will be destroyed after 7 years.

The research information you provide will be used for the purposes of research only and will be stored securely. Only the researcher will have access to this information. After 2 weeks the data will be anonymised (any identifying elements removed) and this anonymous information may be kept indefinitely or published *unusual with the data (sharing it with people outside the EU or using it for teaching) then you will need to edit this notice*].

Appendix C- Focus group interview question sheet

Focus group questions

The purpose of this research is to investigate whether the characteristics observed by Maggie Johnson, a speech and language therapist specialising in SM, over decades of work in this area are present within individuals with Selective Mutism (SM). The project also aims to examine if this checklist of characteristics could then be used to benefit Educational Psychologists' (EPs) hypothesis building, when they are working with children and young people with these presenting needs in order to minimise the delay for intervention.

Therefore, this research will explore the following questions:

- Are the characteristics observed by Maggie Johnson (a speech and language therapist specialising in SM) present within individuals with SM from the perspectives of parents of children with SM?
 - Will awareness of these characteristics be beneficial in helping EPs' elicit testable hypotheses?
- 1) What does the term Selective Mutism mean to you?
 - 2) What are your experiences of working in relation to Selective Mutism?
 - 3) What are your expectations when you hear the word Selective Mutism?
 - 4) What would you deem are the characteristics of Selective Mutism?
 - 5) Is Selective Mutism an area you are confident in?
 - 6) If answered no to the top question, what do you think could help you become more confident in your hypothesis building and working with Selective Mutism? ... Would a checklist of characteristics be helpful?

Prompts and probes

- Can you tell me more about that?
- If this happened how?
- What did you mean when you said...
- It sounds like you are saying, "...". Is that a fair summary?
- So you are saying ...?

Appendix D- Gatekeeper letters for the social media pages

Date

Dear

I am a trainee Educational Psychologist (TEP), in the School of Psychology, Cardiff University. As part of my degree I am carrying out a study to explore the characteristics of Selective Mutism and their applicability for the role of the Educational Psychologist.

I am writing to request permission to post my thesis questionnaire onto your social media page in order to recruit parents who may like to take part in this study.

For this I will share a link to an online questionnaire, which will be accessed via Qualtrics, an online survey package hosted by Cardiff University. I would be grateful if you would allow me to post this link, via your social media page, to the parents that currently access your page. The online questionnaire will take approximately 14 minutes to complete. Questionnaires will be anonymous. Only anonymised data will be presented in the report so that no individual is identifiable.

The findings will be used to form part of my thesis which will be submitted as a requirement of my doctoral degree. The supervisor of my project shall be Dr Gemma Ellis, School of Psychology, Cardiff University.

Many thanks in advance for your consideration of this project. Please let me know if you require further information.

Regards,

Kathryn Edwards

Student Name:	Kathryn Edwards	Supervisor Name:	Dr Gemma Ellis
Position:	TEP	Position:	Professional Tutor, DEdPsy
E-mail:	edwardskb@cardiff.ac.uk	E-mail:	ellisg6@cardiff.ac.uk

Contact details of Cardiff University's Research Ethics Committee:
School of Psychology, Cardiff University, Tower Building, 30 Park Place,
Cardiff, CF10 3EU; email: psychethics@cardiff.ac.uk

Appendix E- Debrief form focus group

Debrief Information

To participants,

Thank you for volunteering to participate in this study, your participation is appreciated and I hope that you enjoyed taking part.

The purpose of this study was to explore the characteristics of Selective Mutism and their applicability for the role of the Educational Psychologist.

You are reminded that your participatory data will be kept confidential until transcribed, at which point it will be made anonymous and kept on a password protected computer. No names will be associated with any findings within the report.

If you have any further questions about this research, please contact the researcher or Dr Gemma Ellis on the contact details below.

Yours faithfully,

Kathryn Edwards

If you have any questions, please contact us or our project supervisor

Contact details of researchers:

Kathryn Edwards, School of Psychology, Cardiff University, Tower Building, 30 Park Place, Cardiff, CF10 3EU; email: Edwardskb@cardiff.ac.uk

Contact details of Research Supervisor:

Dr Gemma Ellis, Professional Tutor, Doctorate in Educational Psychology, School of Psychology, Cardiff University, Tower Building, 30 Park Place, Cardiff, CF10 3EU; email: ellisg6@cardiff.ac.uk

Contact details of Cardiff University's Research Ethics Committee:

School of Psychology, Cardiff University, Tower Building, 30 Park Place, Cardiff, CF10 3EU; email: psychethics@cardiff.ac.uk

The information provided will be held in compliance with GDPR regulations. Cardiff University is the data controller and James Merrifield is the data protection officer (inforequest@cardiff.ac.uk). The lawful basis for processing this information is public interest. This information is being collected by [*Kathryn Edwards*].

The information on the consent form will be held securely and separately from the research information. Only the researcher will have access to this form and it will be destroyed after 7 years.

The research information you provide will be used for the purposes of research only and will be stored securely. Only the researcher will have access to this information. After 2 weeks the data will be anonymised (any identifying elements removed) and this anonymous information may be kept indefinitely or published

unusual with the data (sharing it with people outside the EU or using it for teaching) then you will need to edit this notice].

Appendix F- Focus group transcript

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Appendix G– Six phases of TA (Braun & Clarke, 2021a)

Phase 1: familiarisation

The researcher closely read and re-read each transcript, and noted any ideas, topics, observations, reflections, or phrases that seemed significant in the margins of the transcript. An example of familiarisation

Exploratory comments	Verbatim extract from transcript	Initial ideas
It seems as though she believes that unfortunately currently children with SM struggle through school, and may only get through school due to their friendships. But also most importantly is the fact that this may be further worsened by the fact that these children cannot advocate for themselves.	Uh, and it's maintained at best. If if children make it through a mainstream school, by. In a way, it's supportive and inclusive. Friendship groups, isn't it the that are are making the best of the situation that they're dealing with, but we don't really have a mechanism, perhaps for asking the young people themselves. Was this what, how you wanted it to be? You know, is this as good as it could have been for you? That's not there.	<ul style="list-style-type: none"> - bleak picture. - maintaining the problem. - Making do with what you can. - Perceptions of others

Phase 2: doing coding

Next initial codes related to EPs' experiences were noted. Equal attention to each data item was given and supporting data for each code was collated.

An example of generating initial codes

Verbatim data extract	Initial codes
the bleakness. I suppose it's partly because I think. By the time sometimes these cases do come to us, and they they are in a position where it's quite extreme, was quite severe um and and all these sort of associated difficulties of being very withdrawn and shut in very emotive and. Um And also you've got at that point a lot of very anxious parents, very anxious staff and and there's a lot of transference of that emotion onto you as the professional.	<ul style="list-style-type: none"> - Bleakness - Severe progression - Late diagnosis - Invoke strong feelings

Phase 3: Generating initial themes

Organisation of codes and relevant excerpts into meaningful groups to identify

potential overarching themes.

An example of theme development

Key finding statements	Explanation/outcome	Theme
Finding: behaviour maintained through supportive and inclusive friendship groups.	EPs mentioned throughout the focus group different aspects that could and do maintain the condition of SM.	Perpetuating factors
Finding: behaviour maintained through nurturing mothers, positively reinforcing the behaviour.		
Finding: behaviour maintained through family members shouting at them, negatively reinforcing the behaviour.		
Finding: behaviour maintained through teachers getting friends of the individual to talk for them.		

An example of identification of codes that combined to create the initial themes

Verbatim extract	Initial codes	Initial theme
um I think it's more effective to run it actually in the school though	Best practice	Role of the EP
What's helped with that actually is the preparation to adulthood materials (nodding from the group), which I quote an awful lot in secondary schools.		
we've raised. Awareness. Quite well and, I think there's a lot more children where people are realizing that sitting back and just waiting and for them to grow out of it isn't enough.		
There are the core characteristics aren't there the the kind of ones that you'd expect around that not speaking in certain social situations and speaking in other social situations that are clear characteristic, especially when there's no uh sort of um language uh reason behind that.	Presenting	The 5 Ps formulation
The other one that we've come across is is children who quite simply don't like the sound of their voices		
same or similar presentation, um and of course every child. Is slightly different in the way that they they present, but you know a failure to speak in certain expected situations.		
And I'm expecting them if they're at secondary school, to have other. You know, school avoidance behaviors probably, possibly depression, um I'm expecting it to be quite entrenched.	Co-morbid characteristics	Expectations
Naturally, I'm inclined to expect a very high level of anxiety (nods from group), and anxiety is probably going to be my guiding hypothesis,		

Phase 4: developing and reviewing themes

Becoming explicit and specific with theme refinement. Reviewing the data set entirely in order to view the themes fit in relation to the data set as a whole.

- During this phase it was decided that actually there was no need for the theme expectations as all the codes within the theme were better placed within the other two themes.

Phase 5: precision matters: refining, defining and naming themes

Themes were reviewed and renamed in order to emphasise EPs perceptions of the condition

An example of the revised themes

Themes	Subthemes
1. Role of the EP	Work undertaken
	More knowledge equates to more cases
	Best practice
	Personal connections with the condition
	Niche speciality
	Accountability
	Limitations
2. 'the 5 Ps formulation'	Presenting factors
	Predisposing factors
	Perpetuating factors
	Protective factors
	Goals

Phase 6: writing matters for analysis

Writing the report of the analysis.



“It’s the fact they’re no trouble to anybody. That’s the problem, isn’t it?”: An exploration of the characteristics of Selective Mutism and their applicability for the role of the Educational Psychologist.

Part 3: The critical appraisal

Word count: 5,635

Critical Account of the Research Practitioner

I liken this thesis journey to the book 'We're going on a bear hunt' (Rosen & Oxenbury, 1989), it started off smoothly but shortly after it became apparent there were many obstacles I would face. This critical account will not only look in detail at several of these obstacles but will also explore the development of:

The research topic; rationale and research questions; the research paradigm; and the research design.

Developing the research topic

I have always been someone who has been fascinated by differing conditions, how they affect individuals, how they present, what does the label mean and how diagnoses are made. For my undergraduate dissertation I explored the effectiveness of a drama social skills group with a group of children with a diagnosis of autism spectrum disorder (ASD), for my master's dissertation I focused on teachers perceived effectiveness of the Neurodevelopment Assessment Unit (NDAU) assessments, and for my collaborative research project I chose to explore Additional Learning Needs Co-ordinators (ALNCos) understanding and perceptions of dyslexia. Which, in hindsight, is probably due to my own experiences of gaining and having a diagnosis and wanting to help others who may be in similar positions. Therefore, I have always naturally gravitated towards these kinds of research projects.

In my first year of training to be an Educational Psychologist (EP) I was given a case to research Selective Mutism (SM) and create an information sheet for a secondary school, before this I had never heard of SM. When I delved into the research for this project it struck me how little there was, especially from the EP world, but also how debilitating this condition can be, despite having generally high remission rates (Alpaslan et al., 2016; Mayworm et al., 2015). Within the research which had been published, the focus appeared to be on treatment (which helped with the case I was working on), with one article on the role of EPs. This article mentioned that it is important for EPs to have an understanding of the current research into the causes of SM as this may enable the EP to have a framework to ensure all relevant information is discussed and, in turn, elicit testable hypotheses (Cleave, 2009), however, as I found out, there is limited research for EPs to work with. From this, I knew I wanted to research this condition in some way, therefore, I

signed up to all the webinars and conferences I could on the subject in order to find inspiration. That inspiration came partly from a training course run by Maggie Johnson (Johnson, 2020, Nov 5), who is a speech and language therapist who specialises in SM, who is heavily cited and revered in SM literature and has co-written the SM resource manual (Johnson & Wintgens, 2017). Within this training Maggie ran through specific characteristics that she had found through her years of working and then mentioned that this was a big gap in the literature. Therefore, I knew then that was something I would love to explore more of. I have always had an interest in specific aspects/behaviour traits of conditions; hence, I knew this would be the project for me. Interestingly my undergraduate dissertation was an observational content analysis based on the triad of impairments in ASD.

Developing the rationale and research questions

Firstly, I set out to explore the hypothesis suggested by Maggie Johnson (that specific characteristics is a gap in the SM literature), by conducting a literature search, what I found suggested that what she mentioned in the training was correct, the lack of research in the area not just within the characteristics is glaring. As mentioned, this is what first drew my attention to the condition when previously working on a case, but through conducting the literature review it became more evident. The original question I wanted to answer in my literature review was ‘what are the characteristics of SM?’ as I wanted to gather a picture of what was out there on the topic. I hoped that this would then guide the direction of my research which it did as there was very little research on specific characteristics, but most importantly I found research to suggest that SM is often misdiagnosed (Bergman et al., 2008; Lawler, n.d.; Schwartz & Shipon-Blum, 2005). To determine whether a systematic or narrative review structure would be most appropriate for this study, I researched the preferred reporting items for systematic reviews and meta-analysis (PRISMA) model. But it soon became apparent that there was very limited research into SM itself, let alone the characteristics of the condition. Therefore, the decision to use a narrative review structure was made (Siddaway et al., 2019). This decision was because I wanted to look into literature that used diverse methodologies and I wanted to connect studies that were perhaps on different topics (SM, SM and ASD and the role of the EP with SM), which Siddaway et al. (2019) suggests is an appropriate way of conducting a narrative review. Although there were 522 papers found for Selective

Mut* on PsycInfo, this is practically nothing when you compare it to the 63,194 papers found for Autis*. Of these 522, only 196 were actually deemed somewhat appropriate for my literature review, as some papers found the word mut* was mutations, others specifically said that SM was not included, a handful of papers did not include SM in the title or abstract, other papers were not in English and papers on treatment of SM alone were excluded due to them being perceived as the 'next step'. At first thought it was believed that maybe this is because it is a relatively new diagnosis, however it is now known this is not the case as SM (first written about in 1877) is older than ASD (first described in 1943) (Driessen et al. 2020; National Autistic Society [NAS], n.d.). Therefore, it may be because SM is an internalised disorder, and as these are seen as being less disruptive, they in turn elicit less research as individuals tend to be less interested in them, despite, the detrimental effect that SM can have on individuals (Cline & Baldwin, 1998; Dean, 2012; Esposito & Clum, 2003; Sharkey & McNicholas, 2008; Zakszeski & DuPaul, 2017). As Cleave (2009) suggests that all EPs should understand research to elicit testable hypotheses, this could potentially create problems. A meeting was set up with Maggie Johnson to discuss the use of her checklist within my own research, which she was happy for me to use. I decided that due to the research on misdiagnosis, particularly the research in how SM often presented similarly to ASD, that I wanted to use the checklist with both groups in order to see if there may be cross overs between specific characteristics or if they may just be present within SM (Steffenburg et al., 2018). As DiBartolo and Grills (2006) found that adults are more likely to observe the social avoidance of the children, it was decided that the questionnaires would not be self-reports. However, the decision to use only parent and carers reported questionnaires was a hard one, as I was slightly worried that EPs may not see the value of a parent reported questionnaire over a teacher reported one. As the questionnaire was primarily around the presenting difficulties and both anxiety studies and studies on internalising disorders have shown that parents are better at reporting than teachers for this issue (Berg-Nielsen et al. 2012; Grills and Ollendick, 2003; Phares et al., 1989; Stanger & Lewis, 1993; Viana et al., 2009; Woo et al., 2007). Researchers have also reported that the behaviour of children with SM may be unnoticed by teachers and school personnel, and that clinical interview with parents are essential for diagnosing the condition, yet teacher interviews are valuable but not essential (Berg-Nielsen et al. 2012; Grills and Ollendick, 2003;

Phares et al., 1989; Stanger & Lewis, 1993; Viana et al., 2009; Woo et al., 2007). Furthermore, as the aim of this part of the research was not only to examine possible characteristics but to also gather a checklist of these for professional use, it would be wise to follow findings of clinical interview research, therefore I believed including only parents/carers was the correct decision. The possibility of creating a checklist is in response to the evidence of misdiagnosis, which suggests that perhaps there may be something missing to help aide the transition from information gathering to generating hypotheses (Cleave, 2009; Driessen et al., 2020; Gensthaler et al., 2020). However, I am aware of some wonderful EPs who do amazing work in the field of SM, so maybe it is just my perception that the EP and professional world requires a checklist of this sort, this lead me to wanting to explore EP views of not only the condition of SM but also whether they feel confident to work with the condition, and/or if they would like more tools to help.

Development of research paradigms (epistemology and ontology)

Slevitch (2011, p.74) mentioned that any scientific enquiry is based on a particular paradigm, which is known as a “world view”. These research paradigms are then subsequently determined by ontological positions, which is our process of knowing and epistemology which leads the researcher to question “how can one investigate whatever he or she believes to be known?” (Slevitch, 2011, p.75). As methods, methodology, epistemology and ontology are closely related and co-dependent, it was important that I established my epistemological and ontological stance, prior to starting the research (James, 2015). I considered positions across the continuum and specifically focused on positivism and critical realism, for this. For positivism I found that its assumption that the world consists of universal laws fascinating, but as Fryer (2020) mentions this is a somewhat shallow approach to causation as there may be many factors impacting on the variables which are not being explored, also the objectivist nature of it did not sit right for me as I am aware that my own biases and research will be impacting on the ‘reality’ that I see therefore, I do not believe that every persons world will produce the same knowledge about universal laws, subsequently, I ruled this philosophical position out. I believe that critical realism builds on the downfalls of positivism as it acknowledges that the world is real but that the knowledge production is fallible, theory-dependent and that meaning, and discourse are important but not the be all and end all (Fryer, 2020). As

Gorski (2013, pg.664) shared, research should be 'realist' in the sense that "it takes a mind-independent nature as a fundamental condition of possibility... but it is also realist in the critical sense that it sees science as a human activity that is inevitably mediated (if not determined by human language and social power)".

The critical realist perspective lends itself well to both descriptive statistics and thematic analysis (TA). For the descriptive statistics, McEvoy and Richards (2006) state that using a critical realist approach should allow for deeper levels of explanation and understanding of the data, therefore I was mindful that this was the reality for each of the parents but that this reality may have been skewed through accessing the SM Facebook groups etc. so that they may have been more aware to look out for some of the characteristics than others who may have not accessed SM specific information. For the focus group and subsequent analysis of TA, the critical realist perspective allows the researcher to retain focus on the reality of the material, whilst making meaning of the participants experiences, and acknowledging the ways in which the broader social context may affect those meanings (Braun & Clarke, 2006). The critical realist perspective seemed appropriate for this piece of research as it was a focus group to explore EP's perceptions of the applicability of a SM checklist in order to aid hypothesis building within the EP profession, therefore, it was important that despite being mindful that meanings may be mediated by socio-cultural connotations, the reality was still discernible through the research process. For example, I was able to draw upon the experiences of the EP within my focus group, whilst being mindful that although we are talking about the same phenomenon (SM) each practitioner will have learnt about SM in varying ways and will have likely experienced the condition in several different ways as well, which may impact upon how they perceive the condition and the subsequent effectiveness of a SM checklist. The critical realist approach was also chosen as it is not only compatible with the purposes of methodological triangulation, but it has been noted to circumvent many of the problems related to "paradigm switching" referring to the fact that some researchers believe that the qualitative and quantitative paradigms are so different that they cannot be merged, whereas critical realism believes that methods should be chosen through the research problem, with the important aspect being how the quantitative and qualitative methods are used, rather than if they are compatible (McEvoy & Richards, 2006, pg.79).

Design

Questionnaires within research have been criticised for not being comprehensive and lacking in reliability and validity (Garratt et al., 2011). Despite this it was deemed that a questionnaire would be the correct choice to answer the first research question as questionnaires are more far-reaching than interviews, which is what was required to have a chance at gathering a well-rounded picture of the characteristics of SM (Adams & Cox, 2008). A focus group was then chosen for the second research question, as they typically allow for a more in-depth discussion, which allows the researcher to get closer to what individuals are really thinking and feeling, which lends itself to a more open-ended dialogue on what EPs think about their work with SM (Copley Focus, 2012).

(i) Questionnaires

For the first part of my thesis the hope was that I would reach as many parents as possible to explore the characteristics of SM, therefore a questionnaire using the characteristics observed by Maggie Johnson appeared to be the best way to do this (Adams & Cox, 2008). Originally, as previously mentioned it was my intention to do two questionnaires one for parents of children with SM and one for parents of children with ASD, with the inclusion criteria being that they have a child with a professional diagnosis of SM or have a child with a professional diagnosis of ASD but not SM, this was chosen in order to know that the child had been seen by a clinician so in theory all answers should be in relation to the diagnoses. I created both using Qualtrics, which I had briefly used before and contacted Facebook groups relevant to each condition to place the questionnaires on their site. All Facebook groups contacted got back to me bar one ASD group to say that I could post on their respective Facebook pages, which I did.

The first issue was that of participants, for the ASD questionnaire I had no participants, despite placing them on Facebook the same time as my SM questionnaire and placing them within well-known ASD Facebook groups. I went back to ethics so I could place it on more groups, but the groups never replied to my gatekeeper letter. In the end I decided that although it would have been good to have an extra lens of whether these characteristics could be present within ASD as well as SM, it was not the be all and end all and really the most important aspects would be that gathered from the parents of children with SM and EPs. I was also mindful that if I waited longer, than that would have a knock-on effect on the focus

groups. I speculated that perhaps the lack of interest in the questionnaire may have been down to the fact that the research was not specifically looking at ASD, so parents that may be interested in helping research may have been put off that it is not specifically there to contribute to the knowledge of their child's condition. For the SM questionnaires I had 62 participants in total fill the questionnaires, this was over the number needed for power which was 52 (yet following the dropping of the ASD questionnaire this was no longer particularly relevant) (Brysbaert, 2019). However, 15 of them did not have a formal diagnosis of SM therefore could not complete the questionnaire. I wondered if a substantial number of parents who access Facebook groups on their children's condition are there as they have little means of accessing a diagnosis, due to the remit debate, therefore that is the only place/way they can access help and support for their children, interestingly this was also speculated by one member of the focus group. I also found it interesting that the participants would only come from the day I put the questionnaire up or the next day but not after that, possibly suggesting that due to the volume of posts that occur in Facebook pages it may be that for future research I should branch out into other modes to secure more responses.

The next issue was that of Qualtrics. For Qualtrics I relied on previous lecture presentations and the expert guidance of university lecturers, yet I still made mistakes, mainly in forgetting to activate the latest version of the questionnaires, which meant not only did the participants access a somewhat confusing (but not bad) questionnaire but when I accessed the findings it appeared as though half of the data was lost. It took around a month to realise what had happened and to find the data that was lost, which meant that the plans for the focus group had to be put on hold. Although this was a huge mistake which at the time, I was not aware of, it has helped me realise how important asking for help is and also how quickly things can go wrong. Although I thought I had checked everything when I sent the links, I will know to simply ask a supervisor to also give it a last minute check over, following this, to know that it is correctly done and that I haven't forgotten anything.

(ii) *Focus groups*

For the next part of the thesis, I was originally going to do a questionnaire and then a focus group, however due to the mix-up with Qualtrics causing delays I felt it best to concentrate on, and put all my effort into, the focus group. I decided this as I preferred having a more in-depth knowledge of the work EPs do with children with

SM and allow for easy reflection on collaborative experiences as opposed to gathering a wide variety of shallower views through questionnaires (Adams & Cox, 2008; Copley Focus, 2012). For this I sent a participant invitation out to EPs via EPNET a popular mailing list for EPs and other education professionals. Smith (2015) states that for a doctorate research study there should be between three-to-six participants for a focus group. Therefore, the aim was six, but if there were at least three participants, the focus group could still continue. Originally, I had four participants who responded to the invitation, however due to circumstances out of our control one participant was unfortunately unable to participate, leaving three for the focus group. However, although it is better to have a slightly bigger group, due to the fact that the inclusion criteria were that they were practicing EPs this means that the participants were part of a homogenous group, which as Adams and Cox (2008) mention would make it easier for them to talk to one another, meaning size was not too much of an issue. On reflection, due to the nature of the study, and how long the focus group was estimated to take (meaning it would take a substantial amount of someone's workday) I probably only gained EPs who already had an interest in SM, which could have possibly biased my sample. For the semi-structured focus group, I used Smith (2015) as a guide on how to conduct a semi-structured interview (however it didn't provide me with information on how to conduct one via Microsoft Teams), as well as using Robson (2015, pg.288) which suggests the incorporation of another researcher in order to make note of who is speaking, note non-verbal interactions and also give feedback on my performance. Therefore, it was decided that another TEP would join me as it may be beneficial to the focus group process.

One of the main hurdles to overcome with the focus group took me by surprise. It was not having no interest whatsoever, it wasn't having internet troubles whilst trying to recruit or conduct the focus group, but it was gaining signed consent. As EPs there is a need to follow the rules of the *health and care professions council* (HCPC), point 1.4 in their standards of conduct, performance and ethics is 'You must make sure that you have consent from service users or other appropriate authority before you provide care, treatment or other services' (HCPC, 2018, Paragraph 1.4) therefore, it should be that they are well versed in consent. From previous experience in this field, I know how frustrating it can be for schools to gain parental consent meaning that my work as a TEP is subsequently delayed, causing frustrations for me. Therefore, I naively assumed that EPs would also feel this

frustration so would provide the necessary consent straight away, but that did not happen. One participant did sign the consent straight away but, for the others who had given their consent forms back without a signature, this meant I had to then chase them up for it (I should note that the ones that were chased up had sent the forms back to me with the express interest that they would be sufficient enough to participate). I don't know if it is because it is a virtual world now which makes it harder for individuals, especially if they are not tech savvy to give consent in this manner, or if maybe within their local authorities they have differing means of individuals providing consent due to the risk of Covid-19 e.g., verbal consent or consent through emailing that they are happy. The Association of Educational Psychologists (AEP) gave the guidance of 'ensure that you have informed consent, i.e., check with parents that they (and the child and / or young person) are happy for the visit to take place and that they understand what it is for and how it will be conducted' (AEP, 2020, pg. 11) within their transitional document following school return after Covid-19. Therefore, it could well be that this is just the way some EPs are now used to working. This will be something, if I were to do another research project in these times, I would need to explore further, to make the research more accessible to those who may not be comfortable with tech or to be in keeping with relevant guidance that has been set by relative associations whilst still being within the realms of the ethical guidance set through the ethics committees.

As the focus groups were conducted on Microsoft Teams this minimised the geographical issues that are usually mentioned within focus group literature (Braun & Clarke, 2013). However, this did bring problems of their own as online conference calls have been linked to exhaustion due to having to work harder to understand non-verbal cues (Jiang, 2020). The hope was that due to this new way of working, EPs would now be somewhat used to working in this manner, so exhaustion was hopefully kept to a minimum.

Finally, as I was the only researcher that analysed the findings this could have potentially led to biases, especially as this is a topic that I am very passionate about. Braun and Clarke (2021, p.8) suggest that researcher subjectivity is the core of reflexive TA, due to the fact that "knowledge generation is inherently subjective and situated", therefore they mention that subjectivity is not a problem but a resource for doing analysis. Meaning that within reflexive TA, researcher bias makes very little sense (Braun & Clarke, 2021). Boyatzis (1998) also states that increased confidence

in one's observations can be thought of as a form of reliability. Therefore, I am relatively confident in my ability to analyse the findings in the most open way, whilst also being mindful that unconscious biases may have been present.

Reflections and conclusions

To conclude, this critical account of the research practitioner has allowed me to analyse and reflect on the process of my research. The limitations and strengths of my project have been discussed above, alongside my decisions in developing the research topic, the research questions, and the research design. Overall, this study was hard, it taught me so much about myself which I am grateful for (but would have preferred I not had to learn them in this manner). This project, much like my small scale research project, showed me my resilience levels and taught me about how to be persistent in the face of setbacks. It has helped me realise that in research it is important to have individuals you can go to for help and that although it is your own project you are not alone, which I think I needed to learn. But, as the beginning mentions there were many obstacles in the way, but I do believe I have now found the bear (Rosen & Oxenbury, 1989).

Contribution to knowledge

Contribution to knowledge and previous literature

Around 296 papers found within the Selective Mut* search were around assessment of interventions following diagnosis of selective mutism (SM), this I found interesting as only two papers (one of which is a thesis) were focused on the characteristics of the condition. It would appear as though the research into SM, despite there being little, has increased too quickly and thus has created a deep crater of lack of information, as it has effectively jumped the early stages of characteristics and aetiology to go straight into treatment of a condition people know relatively little about. This, in my eyes, could be why there is so much misdiagnosis or, in general, a lack of diagnoses of this condition, as Bergman (2008) states there is a lack of standardised measures which directly assess SM symptoms. Therefore, part of this study is to try to address this gap in the literature. The research questions attempted to address several gaps including the characteristics of SM and whether these are applicable for the role of the Educational Psychologist (EP). It is hoped that the findings from this research can be used to potentially create a checklist (similar to that of the dyad of impairments in ASD) that could perhaps help EP's and potentially other professionals who may not be knowledgeable of the condition, to map the needs of the child in order to individualise treatment, which Cleave (2009) suggest needs to be done.

Contribution to practice

The remit of SM is one that is highly discussed amongst families with the condition, suggesting that SM is a relatively hidden voice in the world of conditions. Yet, as research indicated that SM impacts on education and wellbeing, and it is a special educational need it would suggest that it is within the realms of the EP (Boyes Turner, n.d; Zakszeski & DuPaul, 2017). However, as mentioned, there appears to be a lack of research on SM in order to accurately build hypotheses. Although participant numbers were low the questionnaires provided interesting data, with the most 'well known' features of SM being within the 'always' and 'often' sections, which was encouraging to see, as if they were anywhere else there would be a lot of questions. But, even the characteristics within 'rarely' is telling, as it mentions that children can speak if the conversation were to be initiated by someone who was not in their comfort zone but that this is rare. This is interesting because

due to current DSM-V guidelines and basic knowledge of SM, many professionals may dismiss SM if a parent were to say that a child can talk within these scenarios (American Psychiatric Association [APA], 2013). Another example is that of 32 participants mentioning that their child is never able to initiate conversations with people outside of their comfort zone, this may be better guidance for practitioners than the guidance of '*should occur consistently in situations where there is an expectation for speech (such as educational, occupational or social settings)*' as the questionnaires suggest that it is not a consistent pattern (APA, 2013, p.195). Therefore, having this awareness that, although rare, it is possible for a child to speak when spoken to but they will not initiate conversation, could help the child not get misdiagnosed, and help the practitioner create the right hypotheses. However, I do not just believe that this should be limited to EP use, as the characteristics came from the observations of Maggie Johnson, a Speech and Language Therapist (SLT), it would be hoped that this knowledge will also be passed on to the SLTs, and health professionals such as GPs so that each profession in turn can be more knowledgeable of the condition, to provide a more holistic manner of interacting with this condition.

Somewhat selfishly, this research will also contribute highly to my practice, through the focus group I was able to learn valuable ways that other EPs have previously worked with SM, which I can take with me as I progress on my EP journey. I also now have an arsenal of characteristics that can help me with my hypothesis building and I have a greater appreciation for the struggles that parents go through on their journey to accessing help and support for their children, which will make me a more mindful practitioner.

Dissemination

The only way that these findings can contribute to the practice of professionals however is through dissemination. One way this research could be disseminated is through publishing my findings, either through an EP related journal such as 'Educational Psychology in Practice' in the hopes that EPs will not only come across it but that they will read it and adopt what has been mentioned into their practice; or through a wider journal such as the 'Journal of Child Psychology and Psychiatry' in the hope that it would reach a far wider audience. I would also try to make sure to place it on ResearchGate and potentially (if allowed) send the copy to

the Selective Mutism Information and Research Association (SMIRA) in order for individuals to have free access to the paper, which would hopefully mean the research becomes quite far-reaching and far more accessible. Another possibility is that I present the findings to Maggie Johnson in the aim that we can collaboratively produce future work in order to create the checklist and disseminate, for any and all professionals to use if they wish. This view was also shared in the focus group where they mentioned that any form of checklist should be made accessible to all but also that they are easily found when researching the topic. Another, mention from the focus group was potential dissemination via the Division of Educational and Child Psychology (DECP) through helping to create a 'national standard for working with Selective Mutism' guidance, as a participant mentioned that the DECP have currently published one on ASD.

An area which was frequently mentioned during the focus group was the need for there to be training on SM not only within schools but most importantly within EP training courses, therefore, possible next steps of this thesis could be organising discussion around the dissemination of findings in EP training courses across the country, along with Local Authority specific courses for teachers and education staff.

Future research

Although this study tried to incorporate an element of encapsulating the characteristics present within ASD, this did not go to plan. Therefore, due to the high evidence of misdiagnosis around this area, conducting the questionnaire again with this population would be highly desirable, especially if a control group is also incorporated in order to know if the characteristics are specific to SM or not. As previous research suggests that self-reports are a better predictor of anxiety, yet it is best to gather both parent and teacher knowledge alongside it, it may be best that this potential study gathered the checklist information from all groups (DiBartolo & Grills, 2006; Viana et al., 2009).

Another possible avenue for research is that of exploring the remit debate, with the professionals who are apparently involved (EPs, SLTs and Child and Adolescent Mental Health Service [CAMHS] workers). Although this debate is often mentioned during conversations on SM Facebook pages such as the SMIRA parents' group, it would appear that it this has not been explicitly researched. Research into the remit of SM, may provide valuable knowledge into why there

appears to be this debate and what reasons (if any) these professionals will not work with this condition. This has the potential to illuminate the possible misconceptions that these professionals hold and could be the bridge needed in order to change the way this condition is potentially viewed.

Conclusion

To conclude, this section on contribution to knowledge has allowed me to analyse, and reflect upon, not only why I chose this topic to study but also how it could potentially impact me and the wider professional world. I have discussed how this research potentially contributes to previous research through acknowledging a gap that may have been previously overlooked and how it could potentially contribute to the practice of not only EPs but also SLTs and CAMHS workers. Dissemination through research, position papers and training were also discussed with the hope that it could provide potential future research in this area.

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